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Exploring the Role of Social Relationships for Carers of People with Dementia

Jenna-Lorin Spink

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A thesis submitted in part fulfilment of the requirements for the degree of
Doctor of Clinical Psychology

Department of Psychology and Behavioural Sciences, Coventry University;
Department of Psychology, University of Warwick

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List of Abbreviations

NHS	National Health Service
WHO	World Health Organisation
PwD	People/Person with Dementia
OSG	Online Support Groups
DP	Discursive Psychology
DA	Discourse Analysis

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Declaration

This thesis was carried out under the academic supervision of Dr Tom Patterson (Academic Tutor at the Coventry and Warwick Clinical Psychology Doctorate) and Jane Muers (Clinical Psychologist). Dr Simon Goodman (Senior Lecturer at Coventry University) supervised the methodology of the empirical paper.

Apart from these collaborations I can confirm that the intellectual content of the work is the result of my own efforts and of no other person. This work, or any part thereof, has not been submitted for a degree to the University or any other institution.

The nominated journals for publication of chapters 1, 2 and 3 are: Internet Research, Research on Language and Social Interaction and Reflective Practice, respectively (see Appendices A - C for instructions to authors). Authorship of any publications arising from this thesis will be shared with the above supervisors/collaborators where appropriate.

Overall word count: 19,414 (excluding tables, figures, footnotes, references and appendices)

Summary

Informal carers are pertinent in supporting people with dementia. The impact of a diagnosis impacts on the person with dementia, their carers and their social relationship. Caring can be influenced by wider social relationships, the present thesis sought to explore the role of social support within the context of dementia.

Chapter 1 presents a qualitative systematic review of the literature exploring dementia carers' experiences of online support groups. It explores how social relationships with others in a similar situation, over the internet, can support carers with the caring role. The main themes that were drawn out from the studies reviewed were group bonding, emotional support and information gathering, as well as carer perceptions of the unique advantages and disadvantages of online support groups. A critical analysis highlighted methodological limitations with regards to the clarity of the results. Clinical implications and suggestions for future research are also discussed.

Chapter 2 presents a qualitative investigation exploring the construction of identity in carers of people with dementia when interacting in a face-to-face social support group. The study considers the impact of a diagnosis of dementia on carer identity within social relationships and the analysis focusses on the construction of identities within the social context of a support group. The analysis revealed the construction of a group identity that occurs when carers align with the group. The action of this identity is discussed, along with the clinical implications and future research directions.

Chapter 3 puts forward my reflective account of the research experience in relation to the construction of my own identities in social relationships.

Chapter One: Literature Review

‘Perceptions of online support groups for carers of people with dementia: A critical review of the qualitative research literature.’

In preparation for submission to *Internet Research* (see Appendix A for Author Instructions)

Tables are presented within the thesis chapter to aid overall clarity; these will be moved to the end of the paper prior to journal submission as per the author guidelines.

Overall chapter word count (excluding tables, figures and references): 7722

1.0 Abstract

Objective Social support can act to buffer carer burden for carers of people with dementia. Carers can experience barriers to attending face-to-face support groups due to the demands of the caring role. Online support groups can contribute to increasing carer access to social support from others in a similar situation. The present literature review aims to critically evaluate the qualitative findings of studies that have explored dementia carers experiences of online support groups.

Methods The PsychINFO, Medline, CINAHL and Web of Science databases were systematically searched resulting in fourteen articles that met the inclusion criteria for the review. Additional manual citation searches did not result in any further relevant studies being identified.

Results Findings from the studies reviewed indicate that online support groups provided meaningful intervention to carers in terms of group bonding, emotional support and information gathering. A number of perceived advantages and disadvantages of these support groups were also identified.

Conclusions The findings of the present review suggest how valuable online support groups can be for carers of people with dementia to build social relationships with others in a similar situation. This highlights the importance of the role that professionals can play in signposting carers to online support groups. A need for further research is indicated in order to build upon the findings of the present literature review and to more clearly determine whether online support groups provide equivalent benefits to face-to-face groups for carers of people with dementia.

Keywords: dementia, Carers, online support groups

1.1 Introduction

1.1.1. *Dementia*

In most countries across the world, the aging population is currently increasing (World Health Organization, 2015). Older people contribute enormously to society but an aging population also implies an inevitable increase in the number of older people with care needs (Blusi, Asplund & Jong, 2013; European Commission, 2009). The risk of developing certain health conditions, such as dementia, also increases with age. Dementia is characterised by a decline in cognitive function and can be accompanied by behaviour change and communication difficulties (WHO, 2012). In 2015 there were an estimated 46.8 million people with dementia worldwide which has been predicted to double every 20 years (WHO, 2015). However, a recent study reported a reduction in incidence of dementia by 20 per cent with a current estimate of 209,600 new dementia cases per year in the UK (Matthews et al., 2016).

1.1.2. *Caring*

Responsibility for the care of people with dementia (PwD) often falls to family members, generally referred to in the literature as *informal carers* (i.e. not paid) (Blusi et al., 2013; European Commission, 2008). More than a quarter of informal carers spend over 40 hours per week in a caring role (Brodaty & Donkin, 2009). Over two thirds of informal carers of PwD make a sustained commitment to caring for more than one year and over one third for more than five years (Alzheimer's Association, 2007), indicating that caring for a relative or friend with dementia is not a short-term situation. Figures for informal carers of PwD were at 670,000 in the UK in 2012

(Alzheimer's Society, 2012). Caring can be associated with many positive and rewarding experiences (Pagan-Ortiz, Cortes, Rudloff, Weitzman & Levkoff, 2014), however it can also have negative consequences for both mental and physical ill health (O'Dwyer, Moyle & Van Wik, 2013).

1.1.3. Carer Burden

Caring can be associated with social isolation (Ekwall, Sivbery & Hallberg, 2004), high levels of anxiety and depression (O'Dwyer et al., 2013) and increased mortality rates (Gitlin et al., 2003). Caring for PwD has been associated with increased stress and burden compared with caring for someone with a physical disability (Access Economics, 2009), because of the complex needs of PwD, such as personality changes and behavioural difficulties (Moise, Schwarzingier & Um, 2004). The burdens of caring can be further compounded by the fact that many carers are older in age themselves (Larsson, Thorslund & Kåreholt, 2006). In a large-scale study looking at depression in informal carers of PwD, over a third of five thousand participants reported six or more symptoms of depression (Covinsky et al., 2003). Qualitative research has also found that carers of PwD can experience suicidal ideation (O'Dwyer et al., 2013).

1.1.4. Support for carers

Due to the detrimental effects caring can have on the carer, the availability of appropriate support is important. Social support from others can buffer care related stress (Gavrilova, Ferri & Mikhaylova, 2009). Social support groups are available for

people experiencing different health conditions, as well as for informal carers (Chien & Lee, 2008). For carers of PwD, research has provided evidence of the benefits of attending face-to-face support groups, including improved well-being, decreased social isolation and a reduction in depressive symptoms (Chien & Lee, 2008; Llanque & Enriquez, 2012). Some carer support groups are provided by organisations such as the NHS, however they are more typically run by third sector organisations or by carers themselves (Alzheimer's Society, 2007). Many carers of PwD face barriers, such as distance, timing of groups and caring commitments, which prevent them from attending support groups (Karlavish, 2014). For this reason, the internet is now increasingly used to offer or access such support (Potts, 2005).

1.1.5. Online support

Online Support Groups (OSGs) are virtual communities where people can interact with others experiencing similar circumstances, such as having a certain health condition (Potts, 2005). A recent review of the literature has found that internet interventions can be a cost-effective way of delivering interventions for some types of mental health problems, including anxiety and depression (Donker et al., 2015). OSGs try to mirror the support offered by face-to-face groups in a more accessible format (Alzheimer's Society, 2012; McKechnie, Barker & Stott, 2014a). Talking Point, an online support forum had 29,000 members in 2012 (Alzheimer's Society, 2012), which shows their popularity, however a certain level of literacy and technological ability is needed for access (Shaw, McTavish, Hawkins, Gustafson & Pingree, 2000). Video-conferencing support groups are also available and this format may serve to reduce the reported impersonal nature of OSGs to some degree (Marziali, Damianakis & Donahue 2006a; O'Connor Arizmendi & Kaszniak, 2014).

1.1.6. Older adults and the internet

Due to carers of PwD often being above the age of 65 years old themselves, as with the person with dementia (Larsson et al., 2006), the internet divide between older adults and younger populations should be considered when developing OSGs. Research suggests that, over recent years, the number of older people accessing the internet has increased to approximately 58% of people 65 and over (Perrin & Duggan, 2015). As the barriers to internet use decrease (Choudrie, Ghinea & Songonuga, 2013), the internet has been found to reduce isolation and increase well-being for older adults (Jones, Ashurst, Atkey & Duffy, 2015).

1.1.7. Previous reviews

Five previously published reviews have focussed on internet and computer-mediated interventions for carers of PwD. Powell, Chiu and Eysenbach (2008) conducted a review of networked technologies for informal carers of PwD, and found that there were moderate beneficial outcomes on carer stress and depression. The paper was published as a brief report which limits the inferences that can be drawn. Wu, Faucounau, de Rotrou, Riguet and Rugaud (2009) reviewed information and communication technology for carers of PwD, including telephone and internet interventions. It was found that the internet offered a more interactive and attractive intervention format to telephone interventions. Improvements were noted in levels of burden, anxiety, depression and self-efficacy. The review offered a descriptive

summary of the findings, but no comparison of the studies, which again limits conclusions that can be drawn.

Godwin, Mills, Anderson and Kunik (2013) reviewed the efficacy of technology-driven interventions in eight randomised controlled trials. A positive impact on psychological well-being was identified in most of the studies reviewed, however there was a large variability in the interventions of the papers reviewed. Boots, Vugt, Knippenberg, Kempen and Verhey (2014) completed a recent systematic review which looked at the efficacy of internet-based psychosocial interventions for carers of PwD. Again the variability in studies made it difficult to build strong conclusions. The review included a small and limited focus on qualitative findings, which identified an increased knowledge of dementia, increased coping with caring and reduced feelings of isolation. Finally, McKechnie, Barker and Stott (2014b) completed a review of the effectiveness of computer mediated psychosocial interventions for carers of PwD, focussing on quantitative research. The studies reviewed found positive aspects of caring were increased through the interventions, but physical aspects of caring were not affected.

The existing reviews of the empirical literature in this area have predominantly focussed on quantitative research. Bryman (2008) has previously noted that there can be an over-reliance on quantitative research to understand a subjective experience and that, while providing useful information, there are inherent limitations, such as failing to give sufficient consideration to the experiences of carers. In contrast qualitative research seeks to understand experiences from the person's viewpoint (Creswell, 2005). Indeed, McKechnie et al. (2014b) recognised this shortcoming and highlighted the need for a review of qualitative research in this area to provide a deeper insight into carer experience of internet interventions. Previous reviews have

tended to focus on internet and computer mediated interventions as a group, and have focussed primarily on outcomes across a range of interventions rather than exploring one specific type of intervention in more detail. A review of the qualitative research on OSGs would enable conclusions to be drawn about this particular type of internet intervention and may provide insights into the benefits and limitations of such support for carers of PwD.

1.1.8. Rationale

Given the recent growth in the number of carers of PwD, the commitment this requires of them and the associated burden, it is important to understand how these carers can benefit from support interventions. Traditionally, social support groups have taken place in a face-to-face context. However, with the associated barrier of needing to leave the caring role to attend the group, it seems that more carers of PwD are utilising online support (White & Dorman, 2001). Although five prior reviews of ICT support have been conducted, they have been quite generic in their focus and no review has focused solely on internet social support group research.

One previous review (McKechnie et al., 2014b) suggested that a future review of qualitative research, in the area of internet interventions is recommended. Recognising the importance of qualitative research, a number of studies in this area have adopted qualitative methodology, or have included a mixed methodology. The richer understanding of carer experiences that qualitative studies potentially offer (Hasselkus, 1998) complements the more circumscribed symptom-reduction focus of much of the existing quantitative research. Reviewing such studies provides an opportunity to synthesise and critically appraise this body of research and offers the

possibility of adding depth and breadth to our understanding of an area that currently only has a small evidence base.

1.1.9. Aims

The aim of the present review is to critically evaluate the empirical findings of qualitative studies that have explored online social support for carers of PwD. Within this, particular attention will be paid to:

- Ways in which online forums or support groups provide meaningful interventions to carers of people with dementia.
- Carers' perceptions of the advantages and disadvantages associated with online support groups/forums.

1.2 Method

1.2.1 Search strategy

1.2.1.1 Database search

In order to conduct the systematic literature search of relevant studies four bibliographic databases were used, PsychINFO, Web of Science, Cumulative Index of Nursing and Allied Health Literature (CINAHL) and Medline. The databases were

chosen as they cover psychology, health and social science. Previous reviews in this area were consulted to generate relevant search terms (Boots et al., 2014; McKechnie et al., 2014b) and were also extended to incorporate the social aspect of the support under review. The following search terms were used:

Online OR On-line OR world wide web OR www OR cyber OR web-page OR webpage OR web page OR website OR web site OR web-site OR computer OR internet-based OR e-health OR technology network OR Internet AND Carer OR carers OR caregiver* OR care giver OR care-giver OR family OR family members AND Social networks OR social support OR peer support group OR support group OR self-help group OR self help group OR social support OR social network AND Neurodegenerative diseases OR MCI OR Older Adult OR Older Adults OR Alzheimer's Disease OR Dementia

Carer and caregiver were used to describe people who provide informal support for someone, in an unpaid role, for example family carers. The term caregiver was included as this is how carers are referred to in the United States. No date limit was used on the search as previous reviews have not included an in-depth look at qualitative studies or had a particular focus on OSGs. Both the titles and abstracts of the references produced were assessed for relevance. References that clearly did not focus on dementia, older adults or carers were excluded. It has been noted previously (Emslie, 2005) that qualitative articles can have misleading titles or abstracts and so the initial exclusion was kept quite broad to minimise the chance of excluding relevant studies. Articles that were related to this area were read fully to determine whether they met the inclusion criteria and therefore should be included in the present review.

1.2.1.2. Manual Search

The articles that were deemed relevant for the review were used as the basis for the manual search. The reference lists of these articles were searched and the titles and abstracts were reviewed for relevance. Those that were considered relevant were assessed against the inclusion and exclusion criteria.

1.2.1.3. Inclusion and Exclusion Criteria

Table 1.1. The inclusion and exclusion criteria used in the present review

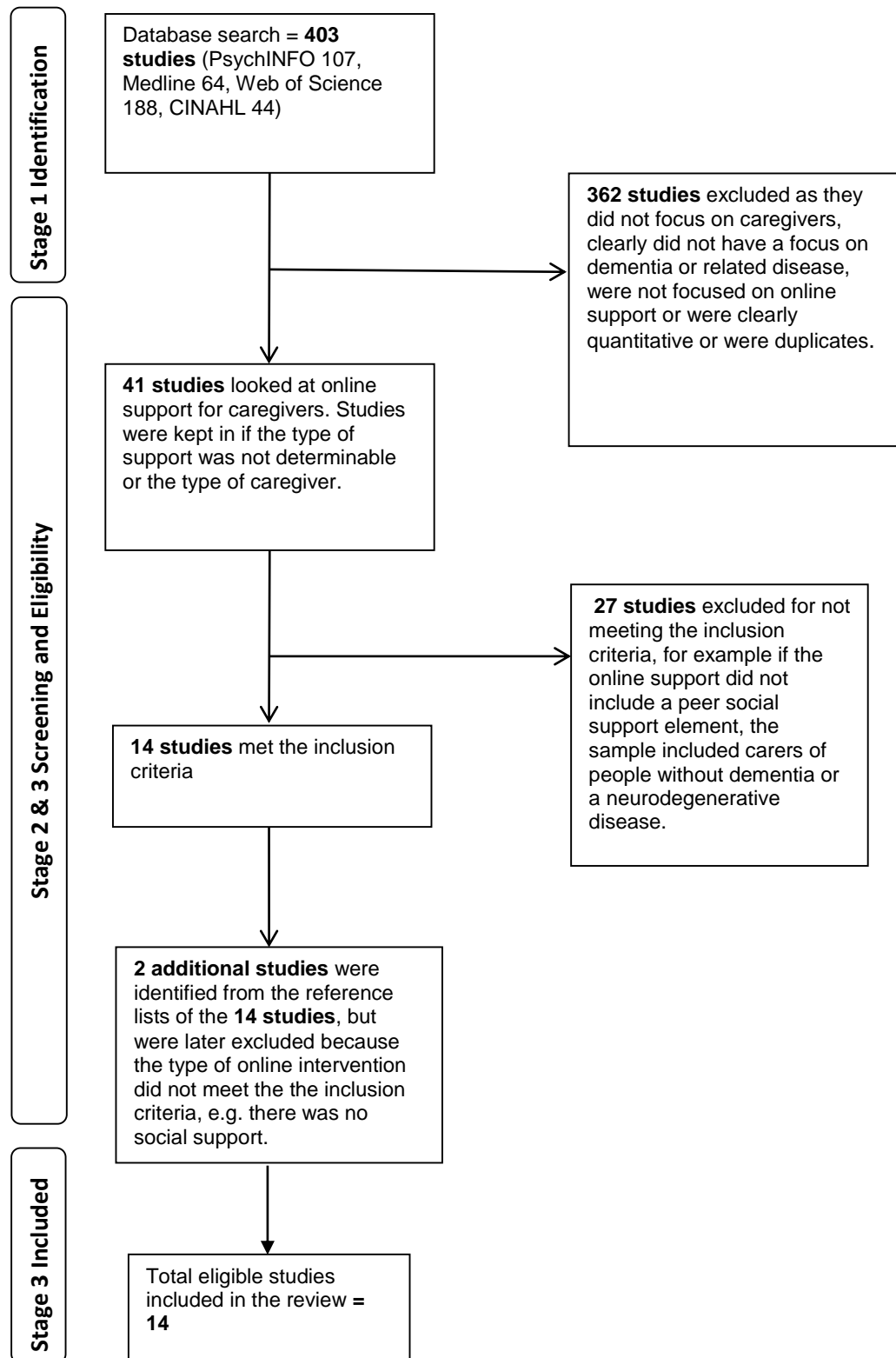
Inclusion criteria	Exclusion criteria
Interventions that were provided through the internet.	Articles not written in English
Internet interventions that included an element of social support with peers e.g. via a forum.	Studies which were dissertations only and had not been published as a journal article.
The sample must use only informal carers, that is, they must not be paid carers such as nursing home staff. However, the PwD may be resident either at home or in an institution.	Studies in which it was not possible to separate data for carers of PwD and other neurodegenerative diseases from carers of older adults with physical conditions such as diabetes.
Study samples must include carers of PwD, where the type of dementia is specified or when it is not. E.g. when it is specified that carers are caring for someone with Alzheimer's Disease or when no specific type of dementia is detailed.	Studies that were not peer reviewed.
Where samples include both carers of people with dementia and carers of people with other age-related neurodegenerative diseases, these will also be included.	Interventions that relied only on the telephone.
Studies must include a qualitative investigation of carer experiences of the internet intervention. Mixed method studies were included, but only the qualitative material is reviewed here.	Interventions that were solely educational, professional support or individual therapeutic sessions.

The inclusion criteria included studies that are not specific to a type of dementia so that the findings of the present review can relate to carers of PwD as a group, rather than carers of a specific type of dementia, such as Alzheimer's disease or Vascular Dementia. If the type of dementia is specified in a study this will still be included in the review.

1.2.2. Search Results

The process of study selection was recorded on a Preferred Reporting Items for Systematic Review and Meta-analysis (PRISMA) flow diagram (see Figure 1.1) (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009). After the study selection process 14 studies remained.

Figure 1.1 Flow diagram based on PRISMA presenting the study selection process. Moher et al. (2009)



1.2.3. Assessment of Quality

After the 14 studies were selected for inclusion in the review they were appraised using a quality rating checklist (See Appendix D). There is debate about the feasibility of quality ratings for qualitative systematic reviews, however they can guide the critical evaluation of studies (Mays & Pope, 2000). The author of the present review initially considered a quality assessment that has been utilised in previous qualitative reviews of carers of PwD (Greenwood, MacKenzie, Cloud & Wilson, 2009), however responses to the assessment did not allow enough discrimination between high and low quality papers. Caldwell, Henshaw and Taylor (2011) use a three-point response scale and cover a wider range of questions to score both qualitative and quantitative studies. It has been recognised that there is a move towards convergence of qualitative and quantitative quality assessments to allow broader observations of the findings (Caldwell et al., 2011). Only the qualitative aspects of the studies in the present review were assessed for quality, but the use of this assessment will allow future comparisons to be made with quantitative studies in the same area. Studies were scored on a scale from 0-36, with a higher score reflecting more quality indicators. Studies were excluded if the score fell below the midpoint (18), in line with the authors guidance (Caldwell et al., 2011). To increase reliability, a second researcher used the same framework to review two of the papers independently which resulted in satisfactory inter-rater reliability (Kappa = 0.77).

1.2.4. Results of the quality assessment

The studies scored between 19 and 34 on the quality ratings checklist, with a mean score of 26.7. The results of the quality assessment establish that although there is some variability, a number of the quality criteria were met across the different studies. All of the studies had clearly stated aims and all but four (Brennan, Moore & Smyth, 1991, 1992, 1995; Pagan-Ortiz et al., 2014) contained a clear abstract that included the key components of the study.

The quality assessment also identified a number of factors that impacted on the quality of the studies. The majority reported qualitative results as part of a larger mixed methods study. Convenience sampling was mainly utilised by these studies to gain enough participants to meet the demands of the quantitative analysis, rather than purposive sampling, often the preferred sampling method for qualitative research (Bowen, 2008; Narayan, Lewis, Tornatore, Hepburn & Corcoran-Perry, 2001). Purposive sampling allows qualitative studies to gain heterogeneity of participants and breadth of perspectives. Convenience sampling does not exclude the opportunity of gaining a heterogeneous sample, however it is less likely (Bowen, 2008).

Limited information about qualitative data collection was given by many of the mixed methods studies. The credibility and justification of the qualitative data analysis was only partially met by the majority of the studies, with three not meeting this quality check at all (Galliane, Shirley & Brennan, 1993; O'Connor et al., 2014; Pagan-Ortiz et al., 2014). All, but two of the studies (Galliane et al., 1993; O'Connor et al., 2014) attempted to inform the reader of the type of qualitative analysis used. However, only

one of the studies (McKechnie et al., 2014a) discussed the position and influence of researchers involved in the study. Furthermore, only two studies (Cristancho-Lacroix et al., 2015; McKechnie et al., 2014a) included the approach that the qualitative analysis took e.g. essentialist, and none of the studies included justification for the type of analysis or the theoretical underpinning. The studies reviewed lacked clear epistemological positions, justification and theoretical underpinning of the qualitative measures chosen.

The most widely used qualitative methods in the studies included in this review were identified as thematic or qualitative content analysis. Thematic analysis has been criticised in the past for not being a method in itself, but rather an element of other qualitative methods (Ryan & Bernard, 2001). However, Braun and Clarke's (2006) paper validates the use of thematic analysis as a method in its own right. Thematic analysis can be utilised under different theoretical influences and so there is an importance in identifying the researcher's epistemological position (Braun & Clarke, 2006). This highlights the concern over the absence of theoretical frameworks given in the studies reviewed as each framework carries individual assumptions that influence the data interpretation. The lack of information about how data collection was completed and the assumptions that drove it can create difficulty when comparing and synthesising the information across studies. It can also hinder other researchers carrying out research on related topics (Attride-Stirling, 2001).

The studies that utilised qualitative content analysis had a data corpus collected from online forum messages. Qualitative content analysis can use both an inductive or deductive approach to its analysis (Polit & Beck, 2012). The one study (White & Dorman, 2000) that used a deductive approach did offer a theoretical explanation of

how these categories were defined, but this was limited, which made it difficult for the reader to follow the analysis and conclusions drawn (Schreier, 2012).

Five of the studies (three of these studies including the same sample) included in the studies reviewed in this paper included carers of people with other neurodegenerative diseases (Marziali, Donahue & Crossin, 2005; Marziali et al., 2006a Marziali & Donahue, 2006b; Torp, Hanson, Hauge, Ulstein & Magnusson, 2008; Torp, Bing-Jonsson, Hanson, 2012). It is important to note that the studies completed by Marziali and colleagues used the same sample for each paper. These samples were included as it was felt that the similarities in presentations across age-related neurodegenerative diseases are likely to create similar challenges in the role as a carer. However, the findings from these studies should be interpreted with caution and recognised that they do not include a dementia only sample.

1.2.5. Analysis

Previous guidelines have stated that formal systematic review or meta-analysis is not suitable when reviewing qualitative papers (Barbour & Barbour, 2003), but that a shared meaning can be found (Campbell et al., 2003). The present review adopted techniques previously outlined (Britten et al., 2002; Campbell et al., 2003), which have since been modified (Emslie, 2005). To analyse the current studies, the context, concepts and participant details for each study were identified. Systematic comparisons were made to ascertain the recurrent themes between the papers. Due to the qualitative methodology focus in this review, convergence and divergence between the themes were explored. The findings that were relevant to the research question will be presented in this review.

1.3 Results

Characteristics of each study and a brief summary of the findings can be found in Table 1.2. The results section will present the findings of the studies in relation to the aims of this review. The studies reviewed in the current study spanned a large frame of time, e.g. from the 1990s to the present time. For this reason, a difference in OSG intervention was found, for example some studies included online forums and others were real-time virtual groups using video-conferencing and avatars. It is important to note these differences when considering the conclusions.

Table 1.2 Characteristics of the studies reviewed.

Author, date, country of origin and quality rating (QR)	Sample size, strategy description and recruitment location	Aims, intervention and topics covered	Data Collection (timing, location, interviewer etc.) and data analysis.	Participant details: gender, age, ethnicity, length of time caring and relationship to person with dementia	Key Findings
Brennan, P. F., Moore, S. M. and Smyth, K. A., (1991). ComputerLink Electronic support for the home caregiver. QR 25	22 were recruited using convenience sampling. Identified from an Alzheimer's Research Registry associated with a large University affiliated hospital and from caregiver support groups sponsored by the Cleveland chapter of the Alzheimer's Association.	Computer Intervention: ComputerLink Network which contained 3 functions: the electronic encyclopaedia, the decision support system and the communications pathway. Accessed from home via computer terminals. Aims: To report the feasibility and initial utilisation of a community computer network designed to assist caregivers in the home.	Content analysis of 57 forum messages was used to determine topical categories of the discussions had. Quantitative data was collected about the percentages of each category used, but only the qualitative data was focused on in this review.	9 male spouses, 10 female spouses, 3 female relatives (other than spouse). Age range 43 – 82, with a mean of 68 years. Length of time caregiving ranged from 1 to 10 years, with a mean of 3.1 years.	The categories that emerged from the discussions were: information about the disease and available community resources, behaviour management and carer coping skills. In addition to the categories that emerged there were also frequent statements of encouragement and support amongst the carers. The written messages suggested a sense of group cohesion, where individuals came together to share common experiences. The ideal technological support for carers should provide emotional support, practical information and increase the carers access to resources. The carer communication area was used most often by the carers, suggesting this is a good area to provide the different elements of support.
* Brennan, P. A., Moore, S. M. and Smyth, K. A. (1992) Alzheimer's Disease caregivers uses of a computer network. QR 21	47 were recruited through convenience sampling identified from an Alzheimer's Research Registry associated with a large university-affiliated hospital, Alzheimer's Association caregiver support groups, and a home mailing sent from the local chapter	Computer Intervention: ComputerLink Network which contained 3 functions: the electronic encyclopaedia, the decision support system and the communications pathway.	Qualitative content analysis of forum messages during a 7-day period. This was to determine whether evidence of social support through interpersonal transactions involving affect,	32 females and 15 males had access to ComputerLink. The mean age of subjects was 60.3 years. Mean length of caregiving (at the beginning of the intervention) was 30 months, range 4 months to 10 years. Relationship of the caregiver to care	In the forum, messages directed to the whole group or to individual users provided evidence of the interactive nature of social support. There was evidence of: Affect in the form of liking and admiration 'I wish you all my good thoughts and prayers for the New Year' Affirmation through acknowledging appropriateness. Aid through asking questions to other carers for advice with caring problems.

	of the Alzheimer's Association.	Aims: To find evidence of social support in the forum messages posted on ComputerLink over a 7-day period.	affirmation or aid were identified.	recipient spouse (57%), adult children (29%) and other family members/friends (13%).	
<p>* Brennan, P. A., Moore, S. M. and Smyth, K. A. (1995).</p> <p>The effects of a special computer network on caregivers of persons with Alzheimer's Disease.</p> <p>QR 23 1</p>	47 participants were recruited through convenience sampling identified from an Alzheimer's Research Registry associated with a large university-affiliated hospital, Alzheimer's Association caregiver support groups, and a home mailing sent from the local chapter of the Alzheimer's Association.	<p>Computer Intervention: ComputerLink Network which contained 3 functions: the electronic encyclopaedia, the decision support system and the communications pathway.</p> <p>Aims: To identify the impact of ComputerLink on social isolation.</p>	Focus groups were used to collect qualitative data of participant's reactions to the intervention. As well as a content analysis of 622 messages on the public bulletin messages. Only the qualitative content analysis themes are reported here.	<p>Participant details were only available for both groups. The comparison did not take part in the qualitative analysis.</p> <p>67% were female, 72% were White. The median age was 64 years. The care recipients were predominantly spouses (68%) or parents (28%) and average length of caring was 34 months.</p>	<p>Focus groups comments reflected the perceived benefit of being able to communicate with peers and professionals at any time of the day. The aspects that they most preferred were communication, companionship, sharing with others with similar experiences.</p> <p>Content analysis revealed that seven themes to the messages that occurred on the forum bulletin. These were: being a member of the group as a mutual support group system, information about the care recipient's situation, emotional impact of caring, development of use of support systems outside the group, problematic interpersonal relationships, self-care and home care skills.</p>
<p>Cristancho-Lacroix, V. Wrobel, J. Cantegreil-Kallen, I. Dub, T. Rouquette, A. and Rigaud, A. S., (2015).</p> <p>A web-based psychoeducational program for informal caregivers of patients with Alzheimer's Disease: A pilot</p>	<p>49 participants in total, 25 were randomly assigned to the control group, 17 finished the protocol and sessions (4 ended their participation, but did not withdraw their consent) and so took part in the qualitative analysis.</p> <p>The recruitment strategy included flyers and posters placed in hospitals.</p>	<p>Intervention: A free, password protected, fully automated website to be used by caregivers. This included 12 sessions based on cognitive behavioural theory as well as access to a forum with other carers.</p> <p>Aims: Qualitative analysis was used to facilitate the identification of subgroups benefiting</p>	<p>Qualitative data was collected through interviews, using open ended questions, at the end of the program by two trained psychologists.</p> <p>Thematic analysis was used to analyse the data, using a semantic approach, driven by analytic interests and an</p>	<p>25 participants in the experimental group, 24 in the control group. Mean age of the experimental group was 64.2 years old (SD 10.3). 16 female caregivers and 9 male caregivers.</p>	<p>Four trends were found in participant's impressions of the program. Within the trends, topics comprising caregivers' opinions were also identified:</p> <p>Caregivers without a clear opinion toward the program</p> <p>These carers did not use the group as felt they did not need to.</p> <p>Caregivers with a clearly positive opinion</p> <p>It was for me – they found benefit in the program. It improved their understanding of the disease or changed their initial beliefs.</p> <p>Caregivers with a qualified opinion</p> <p>I expected something else or it would be better for others.</p>

randomised controlled trial. QR 25	The study was mentioned in consultations with carers and those who were interested left their contact details.	from the program and would guide them to improve the content and methods to evaluate this type of intervention.	essentialist/realist approach.		Caregivers with a negative opinion² This is not for me – Preferring other kinds of support, it came too late or not believing anything could help.
* Gallienne, R. L., Moore, S. M. and Brennan, P. F., (1993). Alzheimer's caregivers: Psychosocial support via computer networks. QR 19	47 were recruited through convenience sampling identified from an Alzheimer's Research Registry associated with a large university-affiliated hospital, Alzheimer's Association caregiver support groups, and a home mailing sent from the local chapter of the Alzheimer's Association.	Computer Intervention: ComputerLink Network which contained 3 functions: the electronic encyclopaedia, the decision support system and the communications pathway. Accessed from home via computer terminals. Aims: To explore interludes and interactions between participants using the ComputerLink Network	No clear qualitative methodology is given, other than an analysis of the messages placed on ComputerLink. Findings are presented in a qualitative manner with extracts of the interludes that take place in the forum messages.	32 females and 15 males had access to ComputerLink. The mean age of subjects was 60.3 years. Mean length of caregiving (at the beginning of the intervention) was 30 months, range 4 months to 10 years. Relationship of the caregiver to care recipient spouse (57%), adult children (29%) and other family members/friends (13%).	Different types of psychosocial support were found in the interactions between people on the public forum. This included the interactions between peers and the interactions between the carers and nurses. Instrumental, Emotional and Spiritual support were found in the interactions and it was found that people could 'hear' others needs in their messages. Providing these interventions were deemed important interventions for carers by the researchers. Concluded that anonymity and the 24/7 access was important functions of the intervention.
** Marziali, E. and Donahue, P. (2005). Caring for others: Internet health support intervention for family caregivers of persons with	34 participants were recruited through collaboration with the local hospital geriatric services at each of the study sites. 17 at each site (remote areas of Canada – Ontario and southern	Intervention: 'Caring for Others' was a password protected website with links to a) disease specific information b) private email c) question and	Data was collected from post intervention follow-up interviews (schedule guided interviews) as well as a full analysis of group process	34 caregivers, 17 from across two study sites. 5-6 in each of the disease groups (Dementia, Stroke, Parkinson's Disease). 26 females, 8 males. The average age of	Four main themes were found during the analysis. Group bonding and support Group members communicated with each other in ways that are parallel to face-to-face group interactions. Personality style: Emotion regulation and cognitive processing. Negative thoughts and feelings were particularly difficult to process. Guilt was associated with

* Brennan et al. (1992), Brennan et al. (1995) and Gallienne et al. (1993) used the same sample of participants, however reported on different aspects of the qualitative analysis and so in the present review were treated as separate studies when reporting the findings in the results section. Brennan et al (1991) reported on a pilot study with a separate sample and will also be referred to separately in the results section.

Alzheimer's, Stroke or Parkinson's Disease. QR 32	Alberta) with 5 to 6 caregivers in each disease group.	answer forum and d) video-conference link for the support group. Aims: to explore whether group process in an Internet videoconferencing environment would emulate face-to-face psychosocial support group process	within the videoconferencing support groups. To do this the group sessions were all recorded. Thematic content analysis of all virtual group sessions was done by using an open coding system.	the caregivers was 67.8 years and they had been providing care for an average of 3.5 years.	frustration for needing to care, which caused people to redouble their caregiving efforts, leading to more stress and upset. Changing relationships: Interpersonal support Irrespective of the relationship to the care recipient the carers spoke about their changing relationships with the dependent family member. Some resented the changes and others felt sad about the changes. Anticipatory mourning Talk included losing the person they had known before the onset of the illness or disease. This was especially evident in discussions of whether or not to arrange a long term placement in a long-term care facility.
**Marziali, E., Damianakis and Donahue, P. (2006a). Internet-based clinical services: Virtual support groups for family caregivers QR 25	34 participants in the feasibility study. This paper also included information from the pilot study which involved 3 groups of 5 – 6 participants in either a face-to-face or videoconferencing group. All of these groups were used to develop the website further for the feasibility analysis.	. Intervention: 'Caring for Others' was a password protected website with links to a) disease specific information b) private email c) question and answer forum and d) video-conference link for the support group. Aims: To see if online group interactions could mirror those of face-to-face interactions seen in the pilot groups.	The data used in this study were the recorded video-conferencing sessions. The group discussions were analysed using thematic analysis to find common themes. An open coding method was used to draw out salient themes. Comparisons were made with pilot studies of face-to-face and online groups.	No further details are given in this study about the participant details, but they are assumed to be as above.	Four main themes: Group bonding and mutual acknowledgement and respect for the collective knowledge about their relatives' disease and coping capacities. Insights into personal, emotional and cognitive processing barriers that interfered with managing their lives in the context of caregiving. Processing the meanings of the changing relationship with the dependent relative. Anticipatory mourning of the loss of the relative as reflected in planning transfer to a long term care facility. These mirrored the themes that were found in the face-to-face and videoconferencing pilot groups. Of particular note was that the group members formed positive bonds with each despite the limitations of the video-conferencing which only allowed one person in the active window at a time.
**Marziali, E. and Donahue, P. (2006b). Caring for others: Internet video-conferencing group intervention for family caregivers of older	66 participants in total. Half (34) were assigned to the intervention condition, as above, and included in the qualitative analysis. The sampling strategy involved identifying	Intervention: 'Caring for Others' was a password protected website with links to a) disease specific information b) private email c) question and	The data used in this study were the recorded video-conferencing sessions. The group discussions were analysed using thematic	26 females, 8 males. The average age of the caregivers was 67.8 years and they had been providing care for an average of 3.5 years.	Four main themes were found: Empathic communication and Understanding. "That's what makes these sessions meaningful....We're not alone and we share the same experiences." Insight into the meanings of the changing relationship with the dependent relative.

adults with neurodegenerative disease QR 27	66 carers of relatives with a neurodegenerative disease from two remote areas in Canada.	answer forum and d) video-conference link for the support group. Aims: A pilot study to evaluate the effects of an innovative, internet-based psychosocial intervention for family carers of older adults with neurodegenerative disease.	analysis to find common themes. Qualitative analysis was also used to analyse post intervention interviews.		<p>"The person that we love is not the same person that she was before."³</p> <p>Insights into personal characteristics that function as a barrier to managing emotions and cognitive processes.</p> <p>"It's my temperament. I am not as patient with people as I should be."</p> <p>Recognition of emotional reactions associated with decision making regarding transfer to institutional care.</p> <p>"It's going to be a very difficult thing to do when the time comes."</p> <p>Despite meeting in an internet format, members were able to offer mutual understanding and support and developed empathic understanding of each other. Experiences paralleled experience of face-to-face support programs.</p>
<p>McKechnie, V., Barker, C and Stott, J. (2014). The Effectiveness of an Internet Support Forum for Carers of People with Dementia: A Pre and Post Cohort Study.</p> <p>QR 34</p>	8, From the 61 participants who completed the baseline survey, 40 expressed an interest in being interviewed about their experiences of using the forum following the 12 weeks and 13 were invited. Interview participants were selected according to inclusion criteria and in order to sample a range of different users.	<p>Intervention: Talking Point the Alzheimer's Society online support forum for carers of people with dementia.</p> <p>Aims: Mixed-methods study to evaluate a well-respected and well-used UK-based online forum for carers of people with dementia.</p> <p>The specific aim of the qualitative interviews was to examine</p>	<p>Seven interviews were conducted over the telephone and one was face-to-face. The interviews lasted approximately 40 minutes.</p> <p>Thematic analysis, taking an inductive, data-driven approach</p>	<p>6 females, 2 males Mean age 61, range 43-84 years old. Ethnicity all White British.</p> <p>All caring for someone with dementia. This is not specifically Alzheimer's Disease as those caring for other types of dementia can also use this intervention.</p>	<p>Overarching domains:</p> <p>Social Similarity</p> <p>All interview participants emphasized the importance of the forum being for people who are in the same situation—caring for someone with dementia. For the most part, this was considered to be a great benefit, although some also noted disadvantages.</p> <p>Unique Aspects</p> <p>Comparisons were made to other interventions. The forum allowed control, including control over frequency of usage and the ability to avoid posts that were too upsetting. Anonymity was a common benefit, including being able to both be more open and honest and to discuss problems that might be uncomfortable to discuss face-to-face. The forum allowed immediate access and response and could be accessed 24-hours a day for as long as need be.</p>

** Marziali, Donahue & Crossin, (2005), Marziali, Damianakis & Donahue (2006a) and Marziali & Donahue, (2006b) all included the same sample. Marziali & Donahue (2006a) included quantitative findings (reflected by the different total number of participants), however the qualitative findings included in the paper were the same as Marziali, Donahue & Crossin, (2005) and therefore this will be referred to as one paper in the results section, but will be accompanied by both references. Marziali, Damianakis & Donahue (2006b), will be referred to as a separate paper as it included qualitative findings of a pilot study. To help the reader distinguish between the 2006 papers they were assigned a and b, because two of the authors are the same.

		participants' detailed experiences of being on the forum and possible positive and negative outcomes.			New Learning All participants described learning new information, and many said that what they had learned on the forum had helped them to become better carers.
Pagan-Ortiz, M. E., Cortes, D. E., Rudloff, N., Weitzman, P. and Levkoff, S. (2014). Use of an Online Community to Provide Support to Caregivers of People with Dementia. QR 26	72 participants took part in the study, unclear how many were involved in the qualitative focus groups as half were assigned to a control group. In Puerto Rico and Massachusetts outreach strategies were used to contact people, like letters, flyers and calls to agencies. In Mexico participants were recruited from caregivers who received social support services at a neurology hospital	Intervention: Website for carers of people with dementia from a Hispanic background. Included information pages and a forum page. Aims: Mixed methods study to assess the website's effectiveness in increasing caregiver's knowledge of dementia, enhanced their self-efficacy for caregiving, enhanced their perceived social support and reduced their perceived burden and emotional distress.	Qualitative data was gathered through open ended questions during focus groups. The researchers then prepared a summary of participant's comments. No information was given about the type of qualitative analysis that took place.	No specific data was given as to whether only a subsample of the participants participated in the qualitative analysis. The 72 participants were recruited from Puerto Rico, Mexico and Massachusetts. Participants were aged between 42 – 78 years old, with more than half being older than 55 years old. Participants had been carers between 3 and 20 years.	Most participants visited the website at least 3 times and as much as every other day. The average time visited was between thirty minutes to an hour. Many people posted comments to other carers on the site. Most indicated that it was an excellent tool for caregivers. As many of the responsibilities associated with caring prevented them from leaving the house the website was an invaluable tool that they could consult for information and support and to speak to others in a similar situation. By talking and writing about what was going on for them it offered a way of letting off steam.
O'Connor, M.F., Arizmendi, B. J. and Kaszniak, A. W. (2014). Virtually supportive: A feasibility pilot	7 of the original 10 recruited completed the study. All participants were recruited from the greater Tucson and outlying regions,	Intervention: Real-time support group accessed using avatars through an internet group. Facilitated by professionals.	At the post survey participants were prompted to leave feedback about their experiences of the group.	All participants were female. Average was 60 years old (range 54 – 70 years old). The mean length since	Participants commented on specific techniques and tools they learned from the researchers. They commented on the general supportiveness of the group. Answers about what improvements could have been made varied, one reported that it would have been useful for all the group members to have the same

study of online support group for dementia caregivers in a 3D environment. QR 24	Arizona, USA, through the community and local university and university hospital campus.	Aims: to investigate the feasibility of online virtual support groups for caregivers of persons with dementia, assessing subjective reports of burden and negative affect and querying the participants as to the utility of the groups.	This project used an intra-case analysis. Because the quantity of data was quite small (N = 7) and constrained by evaluative questions, all of the qualitative responses were read simultaneously.	diagnosis was 3.86 years (SD = 2.23).	relationship to the care recipient e.g. all daughters or all partners as some of their issues were different. Several people reported that they preferred to meet online than in person because having the time to get to groups was difficult.
Torp, S., Hanson, E., Hauge, S., Ulstein and Magnusson, L. (2008). A pilot study of how information and communication technology may contribute to health promotion among elderly spousal carers in Norway. QR 30	19 Participants were referred to the project by GPs or self-referral. The recruitment locations were two municipalities in Eastern Norway. Mixed methods, only the qualitative will be commented on and scored.	Intervention: Pilot online support website, which included information pages and forum Aims: To explore whether family carers were able to make use of the ICT-based intervention and to see if they were able to use it to build an informal support network. Topics covered: reduction in carer stress and mental health problems, knowledge and support networks.	Four focus groups were planned, but one carer was interviewed alone due to other commitments. Two focus groups had five and six participants respectively and a third had two participants (due to illness of the other carers). Qualitative content analysis was used inspired by Kvale (1996) and Malterus (2001). Main themes were drawn out through this process.	8 females; 11 males Mean age 73 years, range 57 to 85. All caring for spouse. Diagnosis of care recipients, 14 cerebral stroke; 5 with dementia Years living with diagnosis, mean 3, range 0-13.	Use of ICT Carers reported a relatively extensive use of the ICT service and using all different aspects of the package, including the discussion forum and videophone. Even if participants didn't post they could still get information and enjoy a sense of belonging with the other carers. Knowledge The information pages were also of importance to gain knowledge about different aspects of the caring role. Having other carers in similar situations to them was of value, not just for emotional support, but also to learn from each other. Social network and informal support The over-riding theme was the informal support gained from the social network with others in a similar situation. This was one of the main areas of satisfaction. Stress and mental health problems Possible positive effects were mentioned, but this seemed vague when compared with other categories. Positive factors included better mood, new supportive friends and focus away from the cared for person.
Torp, S, Bing-Jonsson, P. C., Hanson, E., (2012).	17 participants in total (caregivers of people with dementia or caregiver parents of	Intervention: SafetyNet, which is an ICT website with both	People who had used the internet support were invited to take	The 6 caregivers who had taken part in the pilot had all been carers for	Separate analysis was completed for those who had completed the pilot study and those who had not. Experienced older SafetyNet participants ICT Use The caregivers in this group expressed high

<p>Experiences with using information and communication technology to build multi-municipal support network for informal carers.</p> <p>QR 30</p>	<p>children with disabilities).</p> <p>6 caregivers of people with dementia who had taken part in SafetyNet during the pilot as well (so since 2004).</p> <p>6 caregivers who had not been part of the pilot study (but had taken part in SafetyNet for at least a year).</p>	<p>information pages and peer support forum.</p> <p>Aims: To investigate whether SafetyNet participants could make use of ICT to gain increased knowledge about caring and coping and to determine whether this intervention would enable them to establish informal support networks and thereby adapt and self-manage their situation.</p>	<p>part in focus groups.</p>	<p>people with dementia or stroke. Of the 6, 5 were retired. The median age was 83 years old (60-90 years old).</p> <p>The 6 caregivers who were new to the network were also carers for someone with dementia or stroke. The median age was 60 years old (50-75 years old).</p>	<p>levels of satisfaction and described using the support group extensively to keep in touch with their friends.</p> <p>Social contact and support evident that the carers cared about each other and that giving and receiving emotional support was important to them. There was acknowledgement that the newer participants may have had different experiences and that they saw the more experienced group as a 'clique'.</p> <p>Novice SafetyNet participants</p> <p>ICT use most responded positively, however did not use it extensively like the experienced group. Comments were made that the more experienced group dominated the group.</p> <p>Social contacts and support</p> <p>Novice informants did not find the networks as supportive as the more experienced participants, neither in terms of emotional nor instrumental support.</p>
<p>White, M.H. and Dorman, S. M, 2000.</p> <p>Online support for caregivers: Analysis of an Internet Alzheimer Mail-group.</p> <p>QR 33</p>	<p>532 messages from an open Alzheimer mail-group taken over the period of 20 days in 1998.</p>	<p>Intervention: Mail-group for carers of people with Alzheimer's Disease.</p> <p>Aims: to discern the recurring themes, subjects and patterns of messages.</p>	<p>All messages from the first five days of four months spaced throughout 1998 (March, June, September and December) were printed from the public mail-group. This left a total of 532 messages. Email addresses were noted to monitor frequency as was the caregiver status.</p> <p>Deductive qualitative content analysis of the themes of the 532 messages was used.</p>	<p>Not known</p>	<p>The messages were categorised according to eight subject areas.</p> <p>Information giving/information seeking</p> <p>Many messages included information-seeking requests and they would often receive multiple replies.</p> <p>Encouragement/support</p> <p>This included words of reassurance and acknowledgement and validation.</p> <p>Personal experience</p> <p>Often new members introduced themselves with details of their situation. Others offered updates if they had been absent for a time.</p> <p>Personal opinion</p> <p>Most people would give opinions which involved personal slants on nursing homes, physicians and other professional support. This allowed a way of "letting off steam".</p> <p>Prayer</p> <p>This was only a small number of posts, but involved members who specifically stated that they would be praying for other members and their families.</p> <p>Thanks</p>

					<p>Members gave thanks to others using the group for offering help and suggestions.</p> <p><i>Humour</i> Posts included jokes, funny experiences etc, showing the importance of the role of humour.</p> <p><i>Miscellaneous</i> This was usually housekeeping issues or when someone posted something to the group that was meant to be for an individual.</p>
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1.3.1. *Aim 1: Ways in which online forums or support groups provide meaningful interventions to carers of people with dementia.*

1.3.1.1. *Group bonding*

Bonding with the group was identified in all of the studies reviewed. An overarching theme throughout the studies was the importance of meeting others in similar situations as a way of helping one's own situation. For some the group was perceived as developing into a family and at times, when difficult emotions needed to be shared, it could be more important than family (Torp et al., 2012). All participants in the McKechnie et al (2014a) study emphasised the importance of knowing that they were not alone in what they were experiencing and that finding others in similar situations was perceived by participants as a way of reducing feelings of isolation. For some, a sense of community was established simply by reading the posts of others and did not require the forum group members to post themselves (McKechnie et al., 2014a; Torp et al., 2008). Participants' perceptions, obtained through focus groups or interviews reflected the importance of meeting others in similar situations (Pagan-Ortiz et al., 2014), as did content analysis of group messages which identified "*being a member of the group as a mutual support group system*" as one of the main themes (Brennan et al., 1992; Brennan et al., 1995). Content analysis also revealed that people shared personal experiences after being absent from the group to let others know how they were or in response to questions to support others (White & Dorman, 2000). Messages showed a sense of group cohesion amongst participants developed through shared experiences (Brennan et al., 1991) and peers could '*hear*' each other's '*needs*' in the messages that they posted (Gallienne et al., 1993).

Group bonding was identified in both forums and real-time virtual support groups in the studies reviewed. The virtual support group that used avatars, provided participants with contact with other carers which helped them feel less alone in what they were facing (O'Connor et al., 2014). Observations of initial video-conferencing meetings found that connections were formed with peers through sharing of experiences and continued to be observed throughout the group sessions when carers offered empathic support to each other (Marziali et al., 2005; Marziali et al., 2006a; Marziali & Donahue, 2006b). When carers identified with other's struggles and dilemmas, group bonding was also observed (Marziali et al., 2005; Marziali et al., 2006a; Marziali & Donahue, 2006b).

Establishing a sense of belonging within an online group was not always considered easy. In one of the studies reviewed the participants were combined from those that had taken part in the pilot study (Torp et al., 2008) and a new sample to evaluate the final intervention (Torp et al., 2012). Therefore, the new participants were invited to join a group with already established members that had bonded. The new participants perceived group bonding to be a difficult task and reported that those who had participated for longer had formed a '*clique*' that they did not feel able to join. These participants reported not finding the support very useful and instead felt discussions in face-to-face groups would have been easier, whereas those who had taken part in the pilot study found great support from joining the group (Torp et al., 2012). Cristancho-Lacroix et al. (2015) found that a sense of belonging was not achieved for some participants trialling an internet intervention and for that reason, most of those that did not experience a sense of belonging disengaged with the program. It is important to note that this intervention had a stronger focus on information giving online sessions, than the online forum and the carers that disengaged, left the whole

study. Feedback from these participants included a preference for more contact with peers (Cristancho-Lacroix et al., 2015).

1.3.1.2. Emotional Support

Emotional support through interaction with peers was reported in all but one of the studies (Cristancho-Lacroix et al., 2015) and appeared to be an important reason why carers engaged in OSGs. Emotional messages were usually meaningful and reflected support and encouragement between carers (Brennan et al., 1991, 1992, 1995; Gallienne et al., 1993). Taking part in OSGs was a way of '*letting off steam*' that was not always available in other situations (McKechnie et al., 2014a; Pagan-Ortiz et al., 2014). Content analysis of forum messages found that carers used affect and affirmation when interacting with others which seemed to offer support (Brennan et al., 1992). OSGs allowed the opportunity to share these difficult emotions that were considered harder to share in person (McKechnie et al., 2014a), knowing that their identity was protected through the privacy of the group (O'Connor et al., 2014). The ability to let off steam could also occur by posting frustrations with professional support services (White & Dorman, 2000).

Experiencing emotional states that did not fit with the carers perception of themselves prior to the change in their role was something discussed in video-conferencing groups (Marziali et al., 2005; Marziali et al., 2006a; Marziali & Donahue, 2006b). Participants were able to share feelings of guilt during the social interactions and how this could be associated with feelings of frustration about aspects of caring. Other difficult emotions that were shared included resentment over the change in their relationship with the care-recipient. These negative emotions were difficult to process

alone and sharing with others that listened and were non-judgemental helped to provide insight into what they were experiencing and learn how to manage the emotions (Marziali et al., 2005; Marziali & Donahue, 2006b; Marziali et al., 2006a).

The ability to offer others support also proved important for carers in different studies (Brennan et al., 1992; Marziali et al., 2005; Marziali & Donahue, 2006b; Marziali et al., 2006a; McKechnie et al., 2014a; Torp et al., 2008; Torp et al., 2012), which illustrated to researchers how much the group members cared for each other (Torp et al., 2012). Humour was also used in message posts, including jokes and funny experiences as a way of supporting others with emotional distress and difficult situations (White & Dorman, 2000).

1.3.1.3. Information Gathering

Gaining knowledge about the care-recipient's illness was mentioned in all, but two of the samples (Cristancho-Lacroix et al., 2015; Marziali et al., 2005; Marziali et al., 2006a; Marziali & Donahue, 2006b). Information was needed by carers irrespective of the social support offered by the interventions in the present review and could be gained through information pages provided by the different websites (Pagan-Ortiz et al., 2013; Torp et al., 2008). However, active information seeking to gain information from other group members was also found in forum messages and group discussions during virtual support meetings (Brennan et al., 1991, 1992, 1995; Gallienne et al., 1993; McKechnie et al., 2014a; O'Connor et al., 2014; Torp et al., 2008; Torp et al., 2012). By developing knowledge about the person and their illness, carers felt that it helped facilitate being a better carer and prepared them for how the illness may progress (McKechnie et al., 2014a). Content analysis of forum messages found

questions to other carers were often asked about specific aspects of caring or the illness and responses tended to draw upon personal experiences (White & Dorman, 2000). This overlaps with the first theme (*group bonding*) as the carers were able to share and learn from others in a similar situation (Torp et al., 2008). For some, the sharing of knowledge had made them aware of certain services or benefits that they were entitled to and they reported that gaining this knowledge had helped to reduce strain (Torp et al., 2008). Giving advice to others was also an important part of belonging to a group (Torp et al., 2008).

1.3.2. Aim 2: Carers' perceptions of the advantages and disadvantages associated with online support groups/forums

1.3.2.1. Advantages

OSGs offered unique aspects to support carers of PwD. Discussion forums, when part of mixed intervention studies that included access to information pages and professionals, were perceived to be the most important element of the package (Brennan et al., 1991; Torp et al., 2008). The convenient 24/7 access that the support forums offered was discussed by participants when interviewed as a unique aspect of the groups and considered to be a particular benefit due to the demands of the caring role (McKechnie et al., 2014a; Pagan-Ortiz et al., 2014; Torp et al., 2008; Torp et al., 2012). Carers liked that there were no time limits, there was immediate access and response and that geography was unimportant, for example, access was possible from another country (McKechnie et al., 2014a). The fact that waiting for a response did not take until the next meeting was suggested as important by White and Dorman (2000). The interventions that offered real-time support groups (Marziali

et al., 2005; Marziali et al., 2006a; Marziali & Donahue, 2006b; O'Connor, et al., 2014) also included private access to the intervention website with a forum, so convenient access was also true of these interventions.

One study established that carers using the intervention found that the accessibility of the OSGs allowed them to develop friendships and a support network much faster than with more traditional face-to-face support groups (Torp et al., 2008). Part of the unique way of accessing the interventions also appeared to give carers control over how they used the support (McKechnie et al., 2014a). For example, control allowed carers to only read what was relevant to them and to ignore posts that they were not ready for or that they found upsetting (McKechnie et al., 2014a).

One theme that came through was the need to talk about the care-recipient to others to help the situation. There was a feeling of conflict in sharing information about someone else (McKechnie et al., 2014a; Torp et al., 2008). The anonymity of the groups was discussed in three of the studies (Brennan et al., 1991; McKechnie et al., 2014a; O'Connor et al., 2014). Anonymity provided by OSGs appeared to be a way of combatting the feelings of conflict as carers could be sure that the people they were conversing with would not know the care-recipient. Anonymity allowed carers to be more open and honest when discussing certain problems (O'Connor et al., 2014) and were considered difficult to discuss in face-to-face situations (McKechnie et al., 2014a; Torp et al., 2008). Although anonymity was not overtly outlined in all study findings it was reflected in the themes that were presented (Marziali et al., 2005; Marziali et al., 2006a; Marziali & Donahue, 2006b) and seemed to be reflected in *emotional support* presented above.

1.3.2.2. Disadvantages

Although OSGs offered some unique advantages, some disadvantages were also highlighted in the studies that were reviewed. Some carers expressed disappointment in the lack of human contact available in the online intervention offered (Cristancho-Lacroix, 2015). An advantage of OSGs mentioned above was the accessibility and the availability of answers to questions when needed. However, as many of the groups were asynchronous (i.e. communication did not occur at the same time, as people connected to the group at different times), there were times when responses were not available straight away (McKechnie et al., 2014a; Torp et al., 2008). The design of the forum did give the ability to consult previous posts for answers when responses were not readily available and answers could be found that way (Torp et al., 2008).

The development of real-time virtual support groups has developed the opportunity of receiving answers to questions straight away without needing to leave caring responsibilities and have also enabled the more physical aspects of communication, for example, hearing others voices and seeing facial expressions (Marziali et al., 2005; Marziali et al., 2006a; Marziali & Donahue, 2006b; O'Connor et al., 2014). The utilisation of avatars has also allowed this to be done with identity protected, so not to reduce anonymity (O'Connor et al., 2014). The real-time virtual support groups have been part of intervention packages that have also included access to a forum, which still enables contact with others whenever needed.

One consequence of carer anonymity amongst groups was reported as the opportunity for inappropriate and judgemental posts to occur on the forum pages and

at times these posts were found to be upsetting (McKechnie et al., 2014a). It seemed important for forums to have reviewers check the content of public messages to reduce this happening. However, the control that carers experienced over what they looked at allowed them to be active agents and so certain posts could be ignored if necessary (McKechnie et al., 2014a).

Some studies included in the review analysed public support groups for carers of PwD (McKechnie et al., 2014a; White & Dorman, 2000), whereas other studies recruited participants to closed interventions for evaluation. As mentioned in the '*group bonding*' theme, although only present in one study (Torp et al., 2012), group members who joined an already established closed OSG found it difficult to develop a social network with others and to gain a sense of belonging.

1.4 Discussion

The aim of the present review was to critically evaluate the empirical findings of qualitative research into OSGs for carers of PwD. Specific aims were to evaluate in what way OSGs can offer meaningful intervention to carers of PwD and what were the advantages and disadvantages of OSGs as perceived by carers. Findings from the studies reviewed indicate that OSGs provide meaningful interventions for carers of PwD in three distinct ways, through group bonding, emotional support and information gathering. Group bonding referred to the process of meeting others who were in a similar situation and forming a relationship with the group which offered the carers support. Bonding with the group created a reduction in feelings of loneliness and isolation as perceived by carers and cohesion between group members was developed through shared experiences. Consistency was found with the findings of

studies evaluating face-to-face support groups, in that joining such groups reduced feelings of loneliness and isolation (Chein & Lee, 2008; Munn-Giddings & Vicar, 2007).

The need for emotional support from others was a clear reason for carer engagement with OSGs. The ability to '*let off steam*' and share difficult emotions, such as guilt, with people who were perceived by the carer as understanding was one support function the OSGs were found to provide. McKechnie et al. (2014a) point out that the ability to '*let off steam*' and feel understood is consistent with therapeutic factors found in group therapy (Yalom & Leszcz, 2005). The ability to offer others support by drawing on one's own experiences to do so was also important. McKechnie et al. (2014a) also point out that the opportunity to offer others support is something that is unique to peer support and linked it to previous research that has suggested having the opportunity to offer others help can increase competence, usefulness and independence (Roberts et al., 1999).

Informational support also emerged as a way in which OSGs provided support across a number of the studies reviewed. Knowledge gained from others in a similar situation was drawn from personal experiences and therefore offered something that could not be found elsewhere. Having the opportunity to develop a better understanding of dementia helped carers to feel more confident in their role (McKechnie et al., 2014a). Confidence and self-efficacy in one's own caring role has been linked to resilience in caring and can result in greater commitment to the role (Gaugler, Kane, & Newcomer, 2007). The advantages of the OSGs included anonymity, availability and accessibility of the support offered (McKechnie et al., 2014a; Pagan-Ortiz et al., 2014; Torp et al., 2008), whereas the disadvantages were mainly the lack of physical cues,

occasionally needing to wait for a reply and difficulties bonding with the group (Cristancho-Lacroix et al., 2015; Torp et al., 2012).

An interesting finding from the present review was the convergence in experiences across the different studies. The reviewed studies were completed across a wide time period (1991 – 2015), had some variability in the OSG interventions, used different methodologies and were completed in different locations and with different cultural groups, yet the importance of OSGs for the participants was a consistent finding across the studies. Methodological differences can be seen in the studies conducted by White and Dorman (2000) and McKechnie et al (2014a). White and Dorman (2000) took a deductive theory driven approach whereas McKechnie et al. (2014a) used thematic analysis and adopted an inductive data-driven approach. Despite these different approaches, they reached similar conclusions, including the importance of sharing with others in a similar situation, encouragement and support and the need for information. Intervention differences are highlighted by Torp et al. (2008) and the studies by Marziali and colleagues. The former offered an online intervention that included a support forum and the latter an online intervention that included a real-time video-conference support group. Despite the intervention differences, convergent findings emerged regarding social networks being formed via the groups and the beneficial emotional support that these networks offered.

Some divergence was also noticed in carer experiences. Most notable was the finding of Torp et al. (2012) where the sample comprised two groups that were enrolled in the support forum at different time points, as mentioned in the results section. Newer participants found it difficult to infiltrate what was perceived to be a '*clique*' that had already formed. This finding deviated from the *group bonding* finding in the other

studies reviewed, however, in those other studies participants joined the groups at the same time and therefore the *clique effect* is less likely to have been present. It would be useful for future research to explore this issue further as it highlights the need for careful thought to be given to the process of recruitment to closed OSGs.

It was not possible to draw any strong conclusions as to whether the use of OSGs can meaningfully replicate the perceived benefits of face-to-face support groups based on the findings of the present review. However, studies did make comparisons between the benefits of face-to-face groups and OSGs in both video-conference support groups (Marziali et al., 2005; Marziali et al., 2006a; Marziali & Donahue, 2006b) and online forum discussion boards (Brennan et al., 1992, 1995) and reported that elements of OSGs mirrored those found in face-to-face support groups. To make these comparisons Marziali et al. (2006a) completed a pilot study that used content analysis to consider themes in face-to-face groups and a preliminary trial of the OSG. Brennan and colleagues (1992 & 1995) drew upon pre-existing theoretical definitions of social support which suggested three elements to social support, affect, admiration and aid (Antonucci, Fuhrer & Jackson, 1990) to make these comparisons. The core value of face-to-face groups seems to be reciprocity through the peer support that is offered which carers use to gain empathy, knowledge and emotional and practical information (Munn-Giddings & Vicar, 2007). This value and the resulting gains for carers can be seen in the findings of the present review.

1.4.1 Research Implications

Previous research into face-to-face support groups has identified the importance of meeting others in similar situations to support a reduction in isolation and improved understanding of dementia (Chien & Lee, 2008). A previous review of studies of face-to-face support groups concluded that they can help to improve psychological well-being and reduce carer burden (Cooke, McNally, Mulligan, Harrison, & Newman, 2001). Findings from the present review suggest that OSGs provide emotional, informational and social (group bonding) support. There is currently a lack of research that compares face-to-face support groups and OSGs. Future research in this area may help to elucidate whether the perceived benefits of face-to-face support groups can be meaningfully replicated in OSGs and vice versa. Whatever the findings of such research, the present review highlights a number of benefits of OSGs for carers and in the current economic climate where services are being reduced (McKechnie et al., 2014a), they can also offer a cost-effective way of delivering interventions (Donker et al., 2015).

The papers in the current review span from 1991 to 2015 and across this time period, technology has continued to develop. The changes in technology are reflected by the different types of OSG that are now available for carers of PwD. For example, technological advances have allowed OSGs to develop from a reliance on the use of email bulletin boards and online forums to real-time video-conferencing and the more recent incorporation in some instances of the use of avatars. The range of different formats in which OSGs may be set up has meant that research into OSGs reflects this variability, thus making it hard to draw firm conclusions across the body of qualitative studies reviewed, however convergence in the results was found. Future

research would benefit from making comparisons between the different types of OSGs, perhaps utilising mixed methodologies which would allow both formal measurement of benefits and outcomes and qualitative description of participant's perspectives of the groups. This could help to determine whether certain carers or certain types of carers may have preferences for particular OSG formats, or whether particular carer characteristics are associated with finding a certain format of OSG to be more or less beneficial.

The two main methods of analysis used by the papers reviewed were thematic analysis and content analysis. Given that there are many other qualitative methodologies available, it is suggested that future studies should employ different qualitative methodologies that could add a different perspective to the findings and in doing so add depth to the evidence base. IPA studies would provide more information about the lived experience of being a part of an OSG, which could contribute to developing a more in-depth understanding of an area where limited qualitative research has so far been conducted (Shaw, 2010). In a similar vein, Grounded Theory studies could serve to build theoretical models, grounded in qualitative data, of how OSGs may or may not be beneficial to participants (Gordon-Finlayson, 2010).

1.4.2. Clinical implications

The findings of the present literature review provide evidence to indicate that there are a number of different ways in which OSGs provide meaningful intervention for carers of PwD through the provision of group bonding, emotional support and information. Based on those findings, it is clear that OSGs are perceived by carers of

PwD to be beneficial and to be a source of support. These findings indicate a need for continued provision of OSGs to carers of PwD and they complement the findings from reviews of quantitative studies of online support more broadly, which have identified benefits for carers including reductions in stress, depression and burden and increases in self-efficacy and wellbeing (Godwin, et al., 2013; Powell, et al., 2008; Wu et al., 2009).

The current economic climate has often left public healthcare services diminished (Stuckler, Basu & McKee, 2010). In addition, even where face-to-face groups are provided via the NHS and other mental health services, the practical demands of caring will mean that many carers will not be able to attend those groups. OSGs offer an alternative source of support in a format that has been shown to be cost-effective (Donker et al., 2015).

Finally, stringent ethical and professional standards are applied to face-to-face groups set-up in services. It is important that ethical and professional standards are also taken into consideration when developing online services (Marziali et al., 2006a) as well as consideration to ethical issues that might be unique to interventions being provided over the internet, for example how to secure anonymity for those registered.

1.4.3. Limitations

The studies in the current review that scored lower on the quality assessment, tended to lose points for not clearly presenting a justified methodology and for failing to identify and present a rationale of the philosophical background in relation to the study design. The findings from the Gallienne et al. (1993) study should be interpreted with caution as no description was given of the methodology used or the process of data analysis that took place. Similarly, although the O'Connor et al. (2014) study provided a description of the qualitative analysis, this was still not auditable and the qualitative results presented were limited, therefore the findings from this study should be interpreted with caution, in the absence of replication studies.

The existing body of qualitative research in this area is relatively small. For this reason, studies that included carers of people with other age-related neurodegenerative diseases (as well as dementia) were included (Marziali et al., 2005; Marziali et al., 2006a; Marziali & Donahue, 2006b; Torp et al., 2008; Torp et al., 2012). The reason for this decision was that the samples in those studies did also include carers of PwD. In addition, both Parkinson's Disease and Stroke (Aarsland, Andersen, Larsen & Lolk, 2003; Ivan et al., 2004) are associated with an increased risk of developing dementia and can include similar symptoms. It was considered that similarities in the experience of caring for people with these difficulties would be present. Nonetheless, it should be recognised that caring for someone with Parkinson's disease or caring for a person after they have had a stroke may feel qualitatively different to caring for PwD. For instance, the meaning given to each diagnosis is likely to be different. Although no differences were discussed in the

qualitative findings of these studies this factor should be considered when drawing conclusions from the findings of these studies.

The present review focused on exploring social support interventions for carers of PwD as a whole rather than specifying the type of dementia. However, it is important to note that five of the studies included in this review focused on carers of people with Alzheimer's Disease (Brennan et al., 1992; Brennan et al., 1995; Cristancho-Lacroix, 2015; Gallienne et al., 1993; White & Dorman, 2000) and therefore this is likely to impact on the convergence of these findings with studies looking at dementia as a whole as it is possible that there are unique difficulties for carers of people with Alzheimer's Disease not found with carers of people with other types of dementia, such as Vascular Dementia.

Due to the relatively small research area under investigation by the present review there were limited studies that focused only on social support groups delivered over the internet and so studies were included where the intervention included an element of social support (e.g. a forum or bulletin board) as part of the intervention (Cristancho-Lacroix et al., 2015; Pagan-Ortiz et al., 2014,) as well as studies where the main focus was on the social support element of the intervention (Brennan Brennan et al., 1992; Brennan et al., 1995; Gallienne et al., 1993; Marziali et al., 2005; Marziali et al., 2006a; Marziali & Donahue, 2006b; McKechnie et al., 2014a; O'Connor et al., 2014; Torp et al., 2008; Torp et al., 2012; White & Dorman, 2000). A limitation of including these studies is that it is possible that people's experiences of the social support element of the intervention were influenced by experiences of the intervention as a whole. This should therefore be considered in relation to the conclusions that can be drawn from the present review.

1.4.4. Conclusion

The findings of the present literature review highlight a consistent finding across the studies of positive carer experiences of OSGs. In particular, the present review revealed OSGs are important for meeting others in similar situations, bonding with other group members, gaining emotional support and information gathering. The use of qualitative methodologies allowed carer experiences of these groups to be examined in a more in-depth way than could be produced through quantitative analysis. The findings suggest that OSGs are of value for carers of PwD and also that they have some similarities with face-to-face groups. Further research would allow stronger conclusions to be drawn about the similarities and differences between the two types of groups. Clinically, the findings support the use of OSGs by carers of PwD and indicate that professionals should be aware of the benefits of these groups and signpost where appropriate. Further research is needed to more carefully investigate the different formats of OSGs and to determine whether there are particular benefits or disadvantages associated with different formats or whether there may be carer characteristics that relate to preference for one format over another.

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Chapter Two: Empirical Paper

‘A Discursive Approach to Identity: The Construction of a Group Identity in Dementia Carers Contributions to a Face-to-Face Support Group’

In preparation for submission to the *Research on Language and Social Interaction*
(See Appendix B for Author Instructions)

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Key words: Carers, dementia, support groups, discursive psychology, identity

2.0 Abstract

Objective Informed by social constructionism, Discursive Psychology is unique in providing a framework for the empirical investigation of how language is used in social interactions. Little prior research using a discursive framework has been undertaken to explore the social interactions of dementia carers. Of the few discourse analytic studies that have previously been conducted in this area, no study has explored naturalistic discourse among carers of people with dementia attending face-to-face support groups. The present study sets out to address this gap in the empirical literature.

Methods Discourse analysis was used to analyse data from audio recordings of face-to-face support groups for carers of people with dementia. The analysis explored the construction of identity within these groups and the action orientation of those identities.

Results The analysis revealed the construction of a group identity. This identity was used to protect the moral character of carers, serving to free them to talk about difficult challenges they face in their role as informal carers. The group identity also achieved a collective power which enabled carers to bring about change for the care-recipient and served to affirm the importance of the carers' role.

Conclusions A discursive framework facilitated exploration of the construction of identity by carers of people with dementia attending face-to-face support groups and illustrated how carers use such groups. The findings highlight the benefits that aligning with a group of carers can offer and suggest what can be achieved through the construction of a group identity.

2.1 Introduction

2.1.1. Dementia and Dementia Care

Dementia is an age-related illness defined by DSM-V (American Psychiatric Association, 2013) as '*significant deterioration from a previous level of performance in one or more of the following cognitive domains, attention, executive function, learning and memory, language, perceptual-motor function and social cognition*'. For diagnostic purposes it is now referred to as neurocognitive disorder, but for the purpose of the present paper it will be referred to as dementia. This organic definition of dementia has been criticised for excluding the personal, social and contextual factors that also impact on dementia (Kitwood, 1997).

There will be an estimated one million people with dementia (PwD) in the UK by 2025 and the responsibility of care for PwD often falls to family members (Alzheimer's Society, 2012), usually referred to as *informal carers* in the research literature. Caring can have a significant negative impact on the carer's mental and physical well-being (Schulz & Martire, 2004). It has been suggested that carers of PwD often experience increased strain compared with carers of older adults with physical disabilities, which some have attributed to the challenging behaviours that can be associated with dementia (Moise, Schwarzingler & Um, 2004).

2.1.2. Support for informal carers

Social support groups are available for carers of PwD and offer access to a forum where people in a similar situation meet regularly to try to support one another with the challenges that they face (Munn-Giddings & McVicar, 2007). Research into these groups suggests that they can help to improve the psychosocial well-being of carers of PwD, as well as increasing understanding of the illness and how to cope with the demands of caring (Chien & Lee, 2008; Llanque & Enriquez, 2012).

Online support groups (OSGs), which use the internet to connect people (Potts, 2005), are also available for carers of PwD (Alzheimer's Society, 2012). Both online and face-to face groups come with their own unique advantages and disadvantages. For example, OSGs offer increased accessibility (McKenchie et al., 2014a) but can lack human contact (Cristancho-Lacroix et al., 2015), whereas face-to-face groups offer direct human contact but have the limitation of only meeting at specific times (Walch, Roetzer, & Minnett, 2006).

2.1.3. Social Interaction and Dementia

With the introduction of '*person-centred*' and '*relationship-centred*' care, research has shifted to consider the relational and social impact of dementia (Kitwood, 1997; Nolan, Davies, Brown, Keady & Nolan, 2004). Such research highlights the importance of exploring how a dementia diagnosis affects family members as well as the PwD (Brodaty & Donkin, 2009). This is a valid focus for researchers, given that

relationships are likely to change following a diagnosis with pressure on both the carer and the PwD to continuously adjust to changes in relationship roles and reciprocity (Keady & Nolan, 2003).

Changes in the relationship can threaten individual and shared identity, as the shifts that occur in identity take place within an already established relationship (Wadham, Simpson, Rust & Murray, 2015). Although the impact of dementia is often most apparent in the carer and care-recipient dyad, whole families can accept dementia as part of their collective identity and view it as part of the challenges faced by that family (Garwick, Detzner & Boss, 1994). Thus, social interaction can play a role in the development of identity following a dementia diagnosis for both carers and PwD (Small, Geldart, Gutman & Scott, 1998). Therefore, there is a need to broaden the focus of research in this area from a narrow focus on cognition and cognitive processes to a consideration of social interaction in relation to identity development, with the aim of understanding social processes within the context of dementia.

2.1.4. Discursive Psychology

Discursive Psychology (DP; Edwards & Potter, 1992), which is grounded in social constructionism, offers a theory of assessing identity in relation to social interaction and the context of dementia. DP offers a challenge to classic theories of cognitive psychology. It rejects the idea that cognitive phenomena such as attitudes and stereotypes can be used to infer a truth about what speakers think or believe (McKinlay & McVittie, 2008; Potter & Wetherall, 1987) and takes a critical stance to reality suggesting that it is constructed through social interaction (Edwards & Potter,

1992). The descriptions in talk of events, objects or people are therefore not considered as a neutral reflection of reality or cognition, but are instead viewed as rhetorically orientated accounts which perform actions for the speaker (Abell & Stokoe, 2001).

Discursive Psychologists are not concerned with *what* people say, but rather with *how* different psychological elements, such as identity, are constructed within talk (Kirsi, Hervonen & Jylha, 2000) and what that talk accomplishes in the interaction. Identity is therefore considered to be flexible and is constructed and reconstructed through talk to achieve specific actions within that particular context (Abell & Stokoe, 2001). Discursive frameworks have enabled the exploration of identity in a number of areas within mental health, including schizophrenia (Meehan & MacLachlan, 2008). Limited previous research using a discursive approach has been completed in dementia care or in the context of caring, however relevant studies will now be discussed.

2.1.5. Discourse and caring

Following a diagnosis, informal carers may attribute caring tasks to the established reciprocal relationship with the care-recipient and so not identify themselves as a carer (Montgomery & Kosloski, 2000). Investigating the role of caring for older adults more generally, O'Connor (2007) used a discursive framework to explore the construction of carer identity. A new narrative was needed before carers identified themselves as carers. The carer narrative was found to compete with an already established relational narrative and the findings confirmed that without the social and cultural co-construction of identity, carers often viewed their role as another part of

the relationship. Adopting a carer identity provided positive benefits for carers, including improved and effective use of community support and connection with a wider social network (O'Connor, 2007).

Focussing more specifically on carer identity in dementia, Adams (1998) used a discursive framework to consider the construction of dementia care and suggested that it is important to consider family members position in relation to care. Adams (2000) explored the discursive repertoires assumed by family members caring for PwD in interactions with community nurses. The study outlined how they managed the interface with one another through their language and emphasised how the interactions constructed care-recipient and carer identity within a socio-political context (Adams, 2000). It was through the culturally relevant discourses that social meanings were negotiated and dementia care was constructed and experienced (Adams, 2000). Both of these studies focused on how language between formal and informal carers constructs the identity of PwD and their care and serve to illustrate the use of a discursive framework within this topic area.

Kirsi et al. (2000) analysed stories written for the researchers by husbands about their dementia caring experiences. Using a discursive approach, they found that the caregivers used four different methods of speech to communicate experiences: '*factual*', '*agency*', '*familistic*' and '*destiny*' repertoires. Within these different repertoires of speech, carers adopted different caring identities: '*observer and reporter*', '*responsible caregiver*', '*victim or drifter*' and '*independent actor*'. Identity varied across contexts of written speech and highlighted the diversity of carer experiences. Forbat (2003) looked at the personal account of a daughter caring for her mother with dementia and how this differed from the mother's account. The

findings suggested that talk about the past allowed the construction of the current narrative and could account for tensions in the relationship, by making sense of them through the context of the past. Therefore, the relationship prior to diagnosis can be used in the construction of identity as carer or care-recipient.

Previous published discursive research in dementia care has only examined non-natural discourse, for example interview transcripts or written narratives, however, Lowry (unpublished) has adopted a discursive approach to explore identity construction of carers in natural talk in an OSG. Two prominent identities were identified in the discourse, '*fragile self*' and '*fighter self*' which offered benefits for carers in these supportive exchanges by creating discursive action. The study recognised that the data only reflected discourse among carers of PwD who had chosen to engage in OSGs and suggested the use of DP to explore the construction of carer identity in other social settings as a future research direction.

2.1.6. Rationale

Previous discourse analytic research in the area of dementia care has relied upon non-natural discourse. There is a need to extend this small body of research and address a gap in the existing empirical literature by exploring naturalistic discourse in face-to-face support groups to try to understand how informal carers of PwD use this type of support.

2.1.7. Aims and Research Questions

Through exploring discourse in face-to-face support groups for informal carers of PwD the present study aims to address the following questions:

- i) How do carers construct their identity within face-to-face support groups?
- ii) What is identity used to achieve within the social interactions of carers of PwD in a support group context?

2.2. Methodology

2.2.1. Design

The current study used a qualitative discourse analysis (DA) design adopting the Edwards and Potter (1992) model of DA which has been developed as the main methodological tool for DP. DP is concerned with how people manage psychological matters in everyday life, specifically identities and mental states (Wiggins & Riley, 2010). Discourse analysis views language as active and constructs versions of the world in relation to the social interaction (Edwards & Potter, 1992). This view suggests that language is able to indicate how action and events are constructed within social and cultural contexts (Forbat, 2003; McKinlay & McVittie, 2008). It provides insight into how different identities are produced through spoken and written interactions (Benwell & Stokoe, 2006).

2.2.2. Data corpus

Units of data for discourse analysts are not participants, but representations in language (Kirsi et al., 2000). The corpus of data for the current study was drawn from face-to-face support groups for caregivers of PwD. The groups were open support groups facilitated by different agencies, such as third sector organisations, or that had been developed by carers themselves. Contributors were all informal carers of PwD and included spouses, adult children and adult grandchildren. Some of the contributors were caring for someone who was now in a care-home, some were living with the care-recipient and some cared for the recipient on a daily basis, but lived separately. There was a much larger representation of women who were attending the groups than men.

The data used was naturally occurring extracts from existing support group discussions in the context of dementia care. The data collected was deemed to be conversation that would have occurred regardless of the researcher recordings, however the presence of the recording device may have affected the conversations that occurred (Taylor, 2001). The data collection was considered to yield data that would be the least affected by the researcher, in line with good ethical practice.

2.2.3. Ethics

Ethical approval was obtained from Coventry University ethics committee (see appendix F) before the study began and the study has complied with the ethical

requirements of the British Psychological Society. Those groups delivered by the Alzheimer's Society required a specific ethical application to the society (see appendix G), before local groups could be contacted. This was completed and approval was granted (see appendix H). All information about the contributors was anonymised and the researcher allocated numbers to each contributor.

2.2.4. Procedure

Eight possible face-to-face groups were identified and the facilitators were contacted via email. Once permission was granted, group members were then contacted and given information sheets (Appendix I). Written consent (Appendix J) was gained when the researcher attended each group. Following consent by all group members the meeting was recorded using a Dictaphone. Contributors were given two weeks to withdraw from the study. Withdrawal by one contributor would have excluded that group recording from the analysis. For groups with eight or more attendees, the researcher sat to one side of the group and noted down when each contributor spoke to support transcription.

In the initial data collection phase, five hours of data were collected from four support groups. However, two hours from one support group was inaudible due to the set-up of the group, whereby they split off into smaller groups with no facilitator and separate conversations occurred. For this reason, it was decided to collect additional data, which involved attendance at one more support group. In total, four and a half hours of recorded data, collected from four groups was analysed in the present study. DA has no set criteria for the amount of data that is required. A balance is needed

between enough data to allow an interesting analysis and having too much data that it becomes unmanageable and detrimental to the study (Goodman & Speer, 2007; Wiggins & Riley, 2010).

Once the data was collected, the recordings were transcribed verbatim. The '*simplified version*' (Clarke & Kitzinger, 2004) of the Jeffersonian approach (Wooffitt, 2001) was used, in line with the nominated journal to allow for sufficient detail to be captured of the important aspects of the discourse, without limiting the accessibility to the reader (Clarke & Kitzinger, 2004).

2.2.5. Conducting the analysis

The analysis aimed to explore what members of face-to-face support groups were attempting to achieve with their contributions to the groups. Specifically, the analysis focussed on how identity was developed and what was accomplished by the use of identity within the social interactions, in relation to the research questions. The action orientation of each carer's contributions was considered in line with the Edwards and Potter (1992) model of discourse analysis. To identify the action orientation and discursive devices that were relevant to the research question the data was read and re-read. How identity was developed and what it was used for was evidenced with extracts from the data. The most salient examples from the data that best illustrated the strategies are presented in the analysis section of the present study.

2.3. Analysis

The development of a group identity with others in a similar situation was a prominent feature of the data. Of particular interest was the social construction of carer identity, how group identity was constructed to include new members, how it was maintained and what the actions of the group identity were used to achieve.

A traditional definition of identity can be considered as the sense a person has for who they are (Djite, 2006). This suggests that identity is a constant that remains the same in all situations. It is now generally agreed that identity is influenced by the situation you are in and can change depending on this (Pavlenko & Blackledge, 2004). In the present study identity refers to the sense the contributors have for who they are in relation to the care-recipient and within the context of dementia.

The present analysis also refers to the construction of a '*group identity*'. A traditional definition of '*group identity*' can be classified as a person's sense of belonging to a particular group and how this sense of belonging can influence a person's sense of self (Tajfel, 1978). The identification with a group can occur for many different reasons, for example through a mutual interest, age or job, and may vary depending on how similar someone feels to others in that group. The construction of a '*group identity*' in the present study refers to carers identifying with others in a similar situation to them. The group identity as '*carers of people with dementia*' gives a connection to something that is bigger than them as individual carers. Being able to identify with something that is bigger than the individual allows them to be held or contained in a moment so that they can talk and share difficulties that would be hard to do without the group alignment.

2.3.1. The Social Construction of Carer Identity

By exploring the discourse in the different groups it is possible to illustrate how carers socially construct a carer identity within the context of dementia. In transcript 2, the facilitator (also a carer herself) introduced the question of when members of the group felt they first became carers.

Extract 1:

1. *Facilitator: That is a fascinating question that you can ask everyone in this room.*
2. *Daughter, Mum, when did you become a carer? What day did that happen? And it*
3. *just sort of happens without you and all of a sudden you don't realise that your*
4. *relationship has changed all of a sudden.*
5. *C1: My daughter the other day was saying I am doing far more now for my husband*
6. *now than I was a month ago and I hadn't realised. You know? I was doing more for*
7. *him.*
8. *C2: It's like watching a child grow, isn't it? You see this child grow, but you don't*
9. *notice it and then one day out of the corner of your eye you think, my God!*

The facilitator poses the question of when group members felt they transitioned into the role of carer. The way in which the question is asked (1) makes the topic salient and suggests that the transition can be unclear, with the possibility that people might be unaware themselves when it happens. The contrast made by C1 (Atkinson, 1984), between her daughter's opinion (5) and her own perception (6) draws on the idea that her identity as a carer was co-constructed through social interaction rather than being

a conscious decision that she made to embrace that identity. The contrast also places C1 in a vulnerable position, not realising the extent of what she is doing in her role as carer. The use of the rhetorical question “*You know?*” (6) suggests that not seeing the difference in what was now required of her is something that others will also have experienced. The agreement from C2 (7) offers support to C1’s claim. These discursive devices help to present the carer identity as something that is unintentional and unexpected, that has crept up on all of them. C2’s final statement (8) identifies that the change observed in the care-recipient is also unexpected, which creates further credibility for the unexpected development of the carer identity.

In summary, this extract illustrates that identifying as a carer is not an intra-individual process and identity can be co-constructed in interactions with others. In this case the development of C1’s role was constructed when interacting with her daughter. By interacting with a group of people in a similar situation it offers agreement and supports claims that others have experienced something similar. Interacting with the group further adds to the construction of an individual carer identity.

2.3.2. Constructing a group identity

Interacting with the group gave credibility for claims of an unexpected transition into identifying as a carer. Analysis of extracts illustrate the construction of a collective group identity as the individual carer identities interact. New group members were in attendance in the groups analysed. The following extract taken from transcript 4 introduces C3, a carer attending the support group for the first time. At the beginning of this group each carer introduced themselves and described their personal situation

within the context of dementia care. The extract begins when the facilitator asks C3 if she could to introduce herself.

Extract 2:

1. C3: *No I haven't really got a lot to say sorry (laughs).*
2. C4: *We'll tell us about (.) you are caring for your husband? We'll tell us about him,*
3. *when he was diagnosed and that sort of thing.*
4. C3: *He was diagnosed 6 years ago with um slow dementia, but over the years*
5. *and with his other things that he has got wrong with him, nobody seems to want to*
6. *listen (becomes teary) sorry.*
7. C4: *Yes, it is ok. We all understand. What do you mean when nobody wants to*
8. *listen? You mean your GP or*
9. C3: *No (tears continue).*
10. C4: *It's ok we all understand around this table.*

C3 apologises for not contributing to the conversation (1), reflecting that she is accountable for her failure to add her account. The use of laughter during this first contribution (1) demonstrates that this may be oriented to as a problematic response. C4 (2) however attempts to persuade C3 to speak by inviting her to talk about specific points (a description of her husband's situation) that is more difficult to resist answering. C3 uses '*nobody*' (5) in response, as a method of extreme case formulation (Pomerantz, 1984) to illustrate that she is alone and in a position that is separate from the group. Her tears that accompany this part of the talk convey that this is not a desired or intentional position. A clear group identity is constructed around shared feelings with the use of '*understand*' (7, 10) by C4 and offers an

empathic response to C3 from a shared group with the use of the pronoun 'we' (Van Dijk, 2006) and 'all' to describe the existing group members.

Over the next interactions the group members show solidarity with what they say to try and encourage C3 to develop an affiliation with group members and to align with the group identity. C3 starts by answering a question about whether professionals ('they') have signposted her to a support group in the past.

Extract 3:

11. C3: *Um they have mentioned in the past, but it was the point of walking through*
12. *the door.*
13. C4: *Yes, well that's um. Well you've done well to come today then. So well done.*
14. C3: *Well I found more advice from family and friends than the correct people.*
15. C4: *Well that's what we are. We [are yeah a family].*
16. C3: *[I've got] two children and they both say to me "make sure he's got*
17. *something to drink, he's got his medication, he's got something to eat, make it or*
18. *if he wants to do it himself", which he sometimes does and "then you do your own*
19. *thing". Because if I was to stay with him, I most probably would do him in.*
20. C4: *But that's good that you can get out and leave him like I can.*
21. C3: *I do worry.*
22. C4: *Oh the guilt. Tell me about it.*

C3 uses a disclaimer (1) to emphasise why she has not yet joined a group (Hewitt & Stokes, 1975). C4 meets the disclaimer by offering a statement of encouragement

for her attending the group, however C3 shows resistance to the encouragement by trying to create distance. She uses a generalised other '*correct people*' to refer to professionals and by doing so is able to distance herself from professionals and others who should be there to help. The '*generalised other*', allows her to share that they have been unhelpful (Van Dijk, 2006). This further emphasises her reasons for not attending a support group prior to this time and creates a scepticism for what they can offer. C4 further constructs the group identity by selecting the pronoun '*we*' alongside the repetition of C3's use of '*family*' which is used to achieve a group identity that is comparable to a family and works to suggest that the support offered by the group is at a similar level to unconditional family support. This acts as gentle persuasion for C3 to shift her view of the group and creates the action of her sharing more about her current situation. A shift in C3's identity can be seen as she starts to align with the group. For interactions between these extracts see Appendix K.

As C3 develops a further affinity with the group the next section begins with a disclaimer that her husband believes one thing about her plans, but she constructs a different view for herself, expressing that she does not want to him put in a home.

Extract 4:

23. C3: *You see he thinks I want him put in a home so somebody else can look after*
24. *him and I can have my life, but that's not true and when I, I do say to everybody I*
25. *just feel that he's got something against me.*

This protects C3's moral character as a good carer by asserting her position as one that wants the best for her husband, battling against his accusatory stance. The rejection of her husband's belief and alignment with the group can be seen to do moral work for her identity as a carer (Stokoe, 2012). By protecting her moral character, it builds a case for her to be upset at him, creating a position of accountability for him and vulnerability for her.

Extract 5:

26. C4: *But he's not, for want of a better word, he's not in his right mind. You know*
27. *he's not as he was 20 years ago, is he?*
28. C3: *I know, but I've got to have a life as well as him.*
29. C4: *Absolutely, you definitely need some help.*

Within this interaction C4 tries to emphasise that C3's husband is not the same person as he was by introducing a new point of reference, contrasting how C3's husband is *now* with how he *was* before he had dementia. The action that this tries to create is to support C3 to make sense of her perception that her husband holds inaccurate beliefs about her e.g. that he '*has something against her*'. C3's discursive devices achieve the action of allowing her to receive empathic responses and to further align with the group identity, which in turn allows her to acknowledge what C4 is saying (27). This again acts as a disclaimer to confirm and emphasise her moral character as a carer and allows her to select an individual pronoun to express her needs as separate to the needs of her husband, which leads C4 to offer agreement

that she needs support (28). The group identity as carers works to manage her accountability over a moral issue, how to manage the care of her husband, without damage to her identity as a caring wife.

The final extract from this transcript illustrates the shift that has occurred for C3, since the beginning of the group.

Extract 6:

30. C3: *And that makes me feel better. You know as you say talking here. I feel a*
31. *thousand times better.*
32. C4: *Well look we've all been there*
33. C3: *But you know when you think you are all on your own and we do argue a lot.*
34. *You know and it, it could be.*
35. C4: *Well that's called marriage.*
36. *Group laughs*

C3 now describes the group in a very positive way and further aligns herself with the group (30), which in turn adds to the construction of the group identity. Group alignment further helps C3 to manage accountability over moral issues, of the dilemmas faced by carers of PwD. C3 has gone from not wanting to contribute to the group (1) to constructing the group in a positive manner and has developed her identity as a group member with the use of 'you' to refer to the group (30). C4 reiterates the group identity by using 'we' to describe shared feelings (32). The shift can be illustrated further by comparing C3's initial description of '*nobody seems to*

want to listen' (5) with *'when you think you are on your own'* (33), where the use of the word *'think'* illustrates that this has shifted from a truth to an understanding of what her perception had been prior to aligning with the group. Humour (Attardo, 2015) is used by C4 (35) as a way of addressing a difficult situation with more ease. The group response of laughter constructs a shared understanding of the difficult situations that they all face.

To summarise, these extracts contain examples of a carer moving from a position where she is resisting the shared group identity, offered by others, to accepting the identity and aligning with the group. Established members open up the group by offering welcoming statements and questions as well as constructing the group in a positive way. As she began to align with the group it allowed her to present the conflict and difficulty of her current situation. The alignment with the group identity could be seen to manage the accountability over moral issues associated with the caring role and gain support from others. In turn the ability to manage this accountability further aligned her with the group identity.

2.3.3. Maintaining Group Identity

The previous section illustrated how a group identity is developed, whereas the next section illustrates how group identity is maintained. C6 is attending the group for the first time, however this extract is taken from the second half of the group. It is C5's turn to talk and she uses this opportunity to welcome C6. Rather than using encouragement like in the previous section, C5 uses her alignment with the group identity to illustrate how the group identity can be used to manage accountability over

the moral issues of care. This shows C6 what can be achieved from aligning with the group identity. In turn this further aligns C5 with her established group identity.

Extract 7:

1. C5: *Welcome, because when I came here, you feel someone else has got you*
2. *know, our problems. And it is a great comfort just coming here and listening.*
3. *My husband has got two kinds of dementia. Vascular and Alzheimer's and um he*
4. *is liveable with at the moment. He's very wearing. As you see he does say*
5. *inappropriate things at times and he is very repetitive. He can be very witty, but he*
6. *can be very hurtful with what he says and if he was in his right mind; he would be*
7. *mortified. He's not the man that I married. I have great problems with getting*
8. *him into the shower. He hates having a bath or a shower. So that is one of my*
9. *hard things to do.*
10. C6: *I am very lucky, because (husband's name) has always been*
11. *scrupulously clean.*

C5 gives a welcoming statement to C6 with the use of the pronoun 'you' (1) she constructs the group identity through shared feelings of finding others in a similar situation. The construction of the group identity is developed further by the use of 'our' (2) to refer to collective struggles associated with the caring role (2). In doing so, C5 aligns herself with the group, which gives her the opportunity to present her current situation. C5 creates the idea that her situation is ok (3, 4), but has not been without its difficulties and that there is not a certainty to the length of this manageable period (4). The repetition of 'very' and listing her current problems (4, 5, 6) evokes

emotion and emphasises the difficulty of the situation. The contrast presented in her husband's different presentations (5, 6), acknowledges that her husband has more positive moments and in doing this allows her to share more sensitive and challenging aspects (4, 5, 6). The use of '*right mind*' reduces her husband's accountability for the difficulties, separating him from his illness (6). In line 6 she presents a contrast which serves to create a distance between who he is now compared with before the dementia.

This extract illustrates an established member of the group continuing to draw upon the group identity to protect her moral character as a carer. By presenting her situation after welcoming C6 to the group, it serves as an invitation to C6 to do the same, by demonstrating the action that can be achieved when aligned with the group. However, at this point in the discourse it is met by resistance from C6, who uses the difference in her own situation to create distance.

Towards the end of the discourse C5 continues to direct talk towards C6 and constructs the group in a positive way (12, 13). She provides a further welcoming statement to invite C6 to join the group again. At this point, C6 seems to take her up on the offer and she shows that she is aligning with the group by expressing her wish to return.

Extract 8:

12. C5: *So everyone is different. Welcome to our little team and I hope you come back*
13. *and visit us again.*

14. C6: *I certainly will, yes.*

In summary, these extracts show that the construction of a group identity is maintained through the ability to support carers moral character. This construction works to support the ever changing role of a carer with the new struggles and dilemmas that surface along the caring journey. Continued alignment with the group identity and illustrating, using personal accounts, the moral action that the group identity achieved, was also used as encouragement to new members to align with the group identity.

2.3.4. Initiating Group Action

In addition to the action orientation of managing accountability over moral issues associated with the caring role, the group identity was seen to action carers to overcome a joint problem to reach a common goal, by providing power in numbers. Extract 9 (from transcript 1) provides an example of the carers using their group identity to reach a common goal. C7 starts by reintroducing an issue that has been discussed at a previous meeting, regarding concerns with a day-centre as a collective. She reintroduces this topic to offer feedback about the current situation.

Extract 9:

1. C7: *I was about to report on day care and what's happened. It's just as well that*
2. *they aren't using this room because.*
3. C8: *You know; I was just thinking that. It was going through my mind as it was*
4. *happening you know as the door was opening and I was thinking. That's not good.*

5. C7: They are actually down the bottom end um where their day care used to be
6. um. The room, the room is quite nice, small again, but it has access to the garden
7. which is very nice, a very nice area. So I was taken down there and (name of carer)
8. was waiting there for me the first day I come. So I bring him every Tuesday,
9. Wednesday and Thursday on the bus. I have a volunteer driver who brings him
10. home every day and it has been much better.
11. C8: Oh marvellous. That's much better.
12. C7: Um and she said that he's not (.) restless. Well there is nowhere to wander
13. to and the toilet is near the door when he needs to go. Like (carer) said why go
14. through all of that.
15. C9: I know if they'd just decided that in the first place we wouldn't have had all
16. this problem.
17. C7: Somebody high has decided that all the dementia people ought to be in these
18. two rooms.
19. C9: No, but they are too near the door aren't they? It's automatic.
20. C7: Well exactly.
21. C9: But if we hadn't complained they still perhaps might be in here.
22. C7: But it was so stressful and (name) calls his latest letter. He still has not had a
23. reply from (name of county) council or (name of charity), but it does seem [to be
24. working].
25. C10: [to be working]
26. C11: Yes, yes I was impressed.
27. C7: It does seem to be working.

The use of 'they' (1,19) refers to the family members with dementia attending a particular day-centre. By using this pronoun, it portrays those with dementia as separate to the carers e.g. *us* and *them*, and within the context of this sentence in a

protective manner. The conversation refers to a complaint that they (as a group of carers) made about a day-centre and the resulting move to a different venue. By creating a difference between professionals and carers with the use of *'they'd'*, *'somebody'* and *'we'* (15, 17) the professionals are positioned as a *'generalised other'* (Holdsworth & Morgan, 2007) which in the context of this extract, frees the group to talk about their dissatisfaction with them. Separating themselves from professional groups is used by all contributors during this extract. The word *'just'* (15) highlights that a simple decision making process, made by professionals could have stopped what became a problem (15, 16). The use of the pronoun *'we'* also adds to a clear group identity through shared problems. Repetition of *'working'* suggests a mutual approval and collective agreement of the positive changes that they have been able to create with the shared action that the group identity took (24, 25, 27). This consensus also gives the account credibility and plausibility to the other group members.

28. C9: *So if we hadn't complained then perhaps, they wouldn't have done anything.*

Later in the discourse (28) C9 uses repetition of line 21 to emphasise the group participation in bringing about an action and creates the idea that without the groups shared ability a change may not have been possible.

Extract 10:

29. C11: *If somebody had thought it all out beforehand then you could have done*

30. *without all that.*

31. C9: *It was probably somebody who knows nothing about dementia.*
32. C12: *Well it sounds like between you, you have been able to influence, if not*
33. *educate them.*
34. C7: *Half an hour with us and they should probably have another half an hour with*
35. *us.*
36. C8: *But often that's the problem isn't it. There is somebody higher up that finds*
37. *all these fantastic things, but they don't think the whole thing through.*

The final section creates further division between 'us' and 'them' (Lynn & Lea, 2003), which allows the carers to discredit the decisions made by professionals (29, 31, 36, 37), as ill-advised. It also allows the group to build on their collective identity as knowledgeable carers (32, 33), through affirmation from others in the group. The group action has brought about a change for the benefit of their care recipients (35) and acts as a way to affirm the importance of their role as carers.

In summary, this section highlights how an established group identity works to achieve a common goal. The co-construction of the group identity creates a collective power that allows the group to take action against professionals (who were described as ill-advised) to bring about a change that is beneficial to their care-recipients. This works to reaffirm the importance of their role as carers. The group credibility of the achievements further helps to align carers with the group identity.

2.3.5. Other prominent features of the data

As DA offers such a rich interpretation of data, it is not possible to include all features of the data. Apart from the prominent features identified in the data and discussed above (such as construction of the group/carer identity, maintaining group identity and initiating group action) other notable features of the data were also identified during the analysis. Through the initial stages of the analysis individual identities of the contributors were also constructed in the discourse. It was these individual identities that appeared to interact to construct the overarching group identity. The individual identities seemed to fit a more '*vulnerable self*' and a more '*supportive self*' which was empowered to help those in the more vulnerable position. In the interactions within the discourse analysed an over-representation of positive interactions was also observed, however some disagreement and resistance was identified and it would have been interesting to consider the role of disagreement within the data. Although the discourse was used to gain insight into the construction of carer identity it could also have been used to consider other psychological factors, for example how carers construct the illness of dementia with other carers in relation to their own experiences.

2.4. Discussion

2.4.1. Summary of the findings

The analysis highlights the role that social interaction takes in the construction of individual carer identity, to support the carer in separating this identity from that

associated with relationship roles. When forming part of a support group, the individual identities of carers of PwD interacted to construct a group identity. Construction of a group identity acted to protect the moral character of the carers, freeing carers to talk about their caring role in a supportive place where they were able to criticise the care-recipient without being criticised for being harsh or uncaring. In turn, the way in which the group identity managed accountability over moral issues associated with the caring role further aligned people with the group identity. Established group members were able to use the positive construction of the group identity to encourage new members to align with the group and in so doing, challenged resistance to adopting the group identity. The group identity was maintained for established group members through repeated interactions and was used to support the various struggles experienced by individual carers. Established group members illustrated the benefits of aligning with the group by using examples of the moral work achieved by the group identity in supporting carers.

Identifying oneself as part of the group appears to introduce a dimension of support through building relationships with others that may not be present otherwise. As well as the action of protecting carers' moral characters, the group identity seemed to bring about a group action when needed. A collective *power* was created when members aligned with the group identity, which allowed them to work together to achieve common goals. Individual narratives demonstrate that caring includes dealing with the formal healthcare system. Forming a group identity created a supportive way of negotiating this system. Separating themselves from professionals allowed them to question decisions that did not fit with their perception of correct care. Their position of knowledge was constructed and worked to affirm the importance of their role. The group consensus that was created through the discourse gave their

arguments credibility, which in turn seemed to create a further alignment with the group identity.

The discursive framework used to analyse the natural data from face-to-face support groups shows how important the groups can be for carers. Aligning with the group allows carers to discuss the difficulties and struggles that they experience in their caring role in a supportive and non-judgemental way. The discourse highlighted that part of the caring role is about navigating professional services and that the group identity supported carers to bring about change for the benefit of the care-recipient.

2.4.2. Implications for the research literature

The analysis provides evidence of the role of social interaction in the co-construction of identity for carers of PwD and without this the caring duties are considered an aspect of the existing relationship, rather than a separate identity. This is consistent with previous research (O'Connor, 2007). The need for social interaction to construct the caring role reflects a split in public discourse between '*informal*' and '*formal*' carers. Informal care is often portrayed as a moral disposition which is in contrast to formal caring (Weicht, 2009). This split can be unhelpful for informal carers and the role that they are undertaking (Ungerson, 1987).

There is much to be learnt from studying the development of a collective group identity through informal carers' social interactions within a support group context. The present study highlights that displaying empathy and support to others is a group process and develops a group cohesion, which is similar to what has been found

when exploring the discourse of support groups for people with alcohol dependency (Arminen, 2004). As well as the moral action initiated by a group identity, further action was achieved by the collective power of the group, which is consistent with the idea that group tasks are often represented and tackled in discourse (McKinley & McVittie, 2008). The difficulties that carers can face in managing the healthcare system have been documented in previous research (Peel & Harding, 2013). However, the current study illustrated how aligning with a group of people in a similar situation can help to tackle the issues carers face in relation to services and in doing, so affirm the importance of their role to them. This created positivity for carers and what they are able to achieve.

Social positioning of PwD in support groups has been explored in previous research (Hedman, Hellstrom, Terestedt, Hansebo & Norberg, 2014). The positions developed were observed to facilitate the construction of agentic personae (an active identity). The development of a group identity for carers of PwD can be seen to work in a similar way in the findings from the present study. The agentic identity has been outlined as a way of initiating action in those who are invested in the construction of the identity (Hedman et al., 2014). The parallel processes for both PwD and carers of PwD, reflects the notion that dementia has a social impact on the family network and not just those receiving the diagnosis.

Previous research (Lowry, unpublished) has highlighted the value of studying the construction of different identities in online support forums. This piece of research looked at carer identity of spousal carers of PwD and includes some convergence with findings from the current study. Both studies found that the construction of identity was closely related to the protection of the carers' moral characters. The

present study found that this was not only true for spousal carers, as with the Lowry's (unpublished) paper, but with other carer dyads as well, for example child-parent and grandchild-grandparent. Whereas Lowry (unpublished) found two prominent individual identities the '*fragile*' and '*fighter*' selves the present study is unique in being the first study to explore a prominent group identity in the discourse. Both group and individual identity was similar in that the action that was initiated was to manage accountability over moral issues associated with the caring role and allowed carers to explore difficult experiences in a supportive manner. The individual identities found in Lowry's (unpublished) paper did not seem to construct the collective power that allowed the groups in the present study to accomplish something together, to create positive changes for the care-recipients and affirm their roles as carers.

2.4.3. Future research directions

Further exploration of how group identity develops and forms over time would be useful to build upon the findings from the present study. For example, this could involve research with different face-to-face support groups, or might include tracking the discourse of one group over a longer period of time to develop insight into the flexibility of group identity. As part of this it would be useful to explore group roles using discourse analysis to see whether, like with other groups (Thornborrow, 2003), people have specific group roles that they embody to maintain the cohesion of the group or whether group roles work on a more flexible basis. By exploring the role related discourse it might be possible to understand how discourse is used to focus on different problems and how difficulties are constructed as the most prominent at that time.

Given the role that the group identity played and the actions it initiated in the groups that participated in the present study, it would be useful to explore whether this group identity also serves a function outside the context of the support group. Through the initiation of group action found in the present study, the members were able to bring about change in other social contexts, e.g. so that professionals provided a better service for the care-recipients. This finding is consistent with previous research which has shown carers battling against services through discourse (Peel and Harding, 2013). It would be useful to explore whether group identity brought about change in other social interactions for carers.

One aspect of how carers use face-to-face support groups was explored in the present study, highlighting the value of these groups. As such, it serves to illustrate the use of discursive approaches in increasing our understanding of naturally occurring talk among carers of PwD. The findings also indicate that interactions outside of the caring relationship can provide support for carers and illustrates some of the ways in which this can occur. However, this study has focused only on identity within these social interactions and this area would benefit from further exploration of other dimensions of how carers of PwD use face-to-face groups.

A large representation of agreement and positive interactions between carers occurred in the discourse examined in the present study. This observation is consistent with previous findings of a reluctance to disagree during peer support interactions (Nussbaum, Hartley, Sinatra, Reynolds, & Bendixon, 2004). Previous research has identified a role of disagreement as method of creating a shared understanding within the social context that it is applied (Wenger, McDermott & Snyder, 2002). A few examples of resistance were identified in the present discourse,

suggesting that further research might usefully investigate the function, if any, that disagreement may have within peer support groups for carers of PwD.

2.4.4. Implications for clinical practice

The collective empowerment and knowledgeable position that the carers developed through aligning with the group brought about action and could be of importance for service development and provision. The group identity allowed carers to develop a repertoire of '*expertise-by-experience*' which should be used to develop an authority to services that draws upon service-user experience (Noorani, 2013). '*Expertise-by-experience*' is not just about being part of a particular group it is about living with and working through mental distress (Noorani, 2013). Becoming aligned with a face-to-face support group seems to combine the lived experience with the practicality of meeting others in a similar situation and in doing so provides an opportunity to access a group of carers who can offer expertise for service development.

In one of the group discussions carers were asked how they wanted the structure of their group to be. Importance was given to just meeting as a group to work through their current difficulties, rather than having a set agenda or inviting guest speakers. This appears to reflect a need for such groups to be run in a way that allows them to be open to the current problems of the group members. There often seems to be a need to offer more than a place to meet others, for example facilitating different support interventions within these groups and using outcome measures to evaluate group success. However, the findings from the present study suggest that it is the *being* with each other and enabling social interactions, rather than actively intervening in some way, that is functional for carers.

2.4.5. Limitations

The present study focused on how carers constructed identity during social interactions with others experiencing a similar situation. Discourse analysis is not considered to make subjective judgements; rather it is about making observations of interactions in talk. With DA it is possible to make objective claims as it is possible to see what happens as the data unfolds which is referred to as the DA proof procedure (Wooffitt, 2001). Researcher's claims about interaction can therefore be supported by how contributors respond to each other and how the talk is interpreted. However a focus on how identity is constructed in discourse was influenced by previous research and therefore could be considered subjective. Therefore a limitation of the current study is that the focus was only on identity of carers of PwD. As mentioned in a previous section it would not be possible to look at every observation of the data. For this reason it would be beneficial for future research to explore how language in these social interactions is used to construct other psychological phenomena.

DP uses language to explore how different psychological phenomena are constructed through language. However, limitations of the present study and the DA method is that it is unable to explore the experiences of participants and to interpret feelings and emotions from what participants say as with an IPA approach (Shaw, 2010). So for example it cannot tell us about carer's individual emotional experiences of caring for someone with dementia. DP is also not able to build theoretical models out of the themes developed from what participants say as with a grounded theory approach (Gordon-Finlayson, 2010).

As a method of analysis, DA has been criticised for not including explicit research techniques and instructions for researchers to follow and that there is an over-reliance on the interpretation of the researcher (Morgan, 2010). However, it is felt that a good grasp of the main concepts of DA allows it to be applied to any chosen area. Goodman (unpublished) has developed a guide of how to conduct the DP model of DA and further development in this area may go some way in supporting researchers with the process of analysis.

2.4.5. Conclusion

The present study serves to illustrate the utility of exploring naturally occurring data in increasing our understanding of the development of carer identity in social interactions within the context of dementia. It broadens the focus from a cognitive approach to take account of the role of social interaction. What was most prominent in the data of the present study was the development of a group identity. The group identity was used to achieve particular ends, such as protecting the carers moral characters, enabling them to talk about the struggles they have experienced in relation to the caring role. The group identity also served to build a repertoire of '*expertise-by-experience*', something that can potentially be drawn upon by healthcare professionals working in this area. The discursive findings illustrate the importance of social interaction in fostering positivity in the roles of carers.

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Chapter Three: Reflective Paper

‘Reflections on the Different Identities Constructed Through the Research Process and Clinical Training’

In preparation for submission to *Reflective Practice* (see Appendix C for Author Instructions)

Overall chapter word count (excluding references): 3601

3.0. Introduction

This chapter is a reflective account of my research process and an insight into how my research, clinical and personal identities interact. As a Trainee Clinical Psychologist I am encouraged to use reflective practice to learn from and inform my clinical practice. It allows a critical view of experience to create a deeper self-awareness and an interest in one's actions (Cushway & Gatherer, 2003). As the use of self-reflection furthers one's understanding of the interplay between personal and professional development (Epstein, 1999), it also has relevance to conducting research. I was unaware at the beginning of the research process just how much it would impact on me as a person. As part of my research journey, I became interested in identity and how it can be constructed differently depending on the situation, from what emerged during the analysis of my empirical paper. One of the reasons I was drawn to using discursive psychology for my research was a previously established interest in the application of social constructionism to different aspects of mental health, clinical work and life. For the present chapter I am therefore going to combine both interests to explore, not only my identity during the research process, but throughout my training experience and how this has impacted on my identity in my personal life. Given that a group identity was found in the data discourse, I will also reflect on the group identity of my cohort.

3.1. Identity as a Social Construct

Defining identity can be difficult and there is no established consensus on how to define it. It has been described as a sense a person has for who they are (Djite, 2006). However, researchers now generally agree that there is a multiplicity of

identities (Duszak 2002; Pavlenko & Blackledge, 2004), that actually it can change in different situations.

Social constructionism, as a whole, takes a critical stance towards reality, suggesting that our reality is constructed through social interaction. Social constructionism views identity as co-constructed within society and social groups rather than a consistent entity (Young & Colin, 2004). Therefore, our identity is influenced by what social groups we align with and can change depending on the group that we are with. Indeed, identity can even shift during just one conversation (Davies & Harré, 1990).

In the process of conducting my empirical study, the social influence on identity was seen in the formation of carer identity and how this was not always a direct result of a family member or friend receiving a diagnosis of dementia, rather a result of interacting with others. I also learnt how important the construction of a carer identity was for carers. In a similar way, my own identity is socially constructed by the groups that I interact with. I wonder if it was the social construction of 'Trainee Clinical Psychologist' that influenced my desire to succeed. Getting a place on training, when I was applying was constructed as very difficult and sometimes unobtainable. Perhaps I wanted to succeed in it for that reason. Now I have gone from being someone as part of a group striving towards getting a place on clinical training to actually being a Trainee Clinical Psychologist and my identity has shifted again. What does being a Trainee Clinical Psychologist mean to me? When considering this question I realise the range of the different identities that I have within this role and with friends and family.

3.2. Constructing individual identities

I will now consider the different identities that have been constructed through the process of training. I feel that I have been aware of the different roles that are required throughout my training journey, however this particular focus was brought to the forefront through the reflections of my research experience.

3.2.1. Identity within the cohort

One of the wonderful aspects of training to be a Clinical Psychologist is the opportunity to learn from a number of different skilled practitioners who have worked at honing their skills in particular areas. The construction of my identity at these points I think can vary depending on the area of learning. One element of training that I return to over and over again is the variety of learning opportunities that it offers when developing as a practitioner; the downside of this is wanting to have a knowledge of so many areas it can feel difficult to develop a sufficiently in depth knowledge of any one area. For that reason, in areas of learning where I have limited prior experience, my social position within the group is centred around a lack of confidence and for that reason I shy away from actively adding to the discourse and would probably be described as one of the quieter members of the cohort. However, at times when my prior knowledge is more developed, I can step forward and add more to the discourse of the group. When reflecting on the different positions I can hold within the learning experience for the present paper, I was left wondering about how carers experience learning from support groups. I wondered that if they might also sometimes feel like there is an overwhelming amount to learn and whether at times this can impact on the construction of their identity within that context. Further aspects of the

construction of my identity within the cohort will be discussed in the group identity section.

3.2.2. Identity as a clinician

My role as a clinician and a Trainee Clinical Psychologist really resonated with the idea that identity can shift even within the same conversation, as there are so many different areas to work in and so many different aspects of the role that are socially influenced (Davies & Harré, 1990). In a similar way to the construction of identity in the learning environment with my cohort, there is also a sense of needing to have a breadth of knowledge to succeed in the different placements on training. However, when I consider my identity on placement it is constructed differently to my identity during teaching. During teaching the expectation is to actively listen and take part in the tasks set, but with no prerequisite for previous knowledge. During placement it remains a place of learning, but one where the knowledge that you have developed through training and prior to training is called upon for action. I wonder if, because at those times I am not an active member of the cohort, there is less opportunity to shy away and I am able to construct an identity that portrays more confidence. There are still undeniably times in my clinical role that I feel less confident and this is something that I expect to experience as I transition into a qualified practitioner role and throughout my career.

3.2.3. *Researcher identity*

The identity of researcher has often been one that I have found more difficult to adopt. I wonder whether this is because I have not considered research to be something that I am necessarily good at or have a natural talent for, stemming from a view of myself as not particularly academic. This is an interesting concept in itself, given the academic hurdles that must be negotiated in order to achieve a position on clinical training and also in order to develop in to a qualified Clinical Psychologist. Reflexivity is important in research as it is important for the researcher to understand her/his own subjective position and consider how this influences the study. My own process of reflexivity has led me to consider what particular identities I have drawn upon and which have led me to my particular interests in the current study.

Reflexivity is of particular importance when undertaking qualitative research, where a distinct right or wrong is not present (Berger, 2015). Choosing a methodology that is appropriate to the research question is obviously of great importance, however my own interests have played a part in this decision. I wonder if my lack of confidence and feeling like a relatively new researcher is why I was drawn to a qualitative methodology where determining right or wrong is not the principal task. However, I am acutely aware that thinking qualitative research is a simpler option, when compared with quantitative methodologies, is not the case, because the very nature of trying to understand people is so complex and qualitative methods are accompanied by rigorous quality measures to ensure validity (Yardley, 2000). I was then left considering what else it was about qualitative methodology that fitted with my identity in other areas. I think my identity as a Trainee Clinical Psychologist is counterintuitive to a quantitative methodology. I understand that quantitative research

is of great importance and it is used by services such as the NHS to influence service design. I have also really valued the training that I have received in quantitative methodologies and would always adopt a quantitative approach in instances where it is appropriate to answering the research question. For me though, I tend to more naturally move towards a qualitative research perspective where the goal is to create a richness to the data to try and understand others.

Discourse analysis was used for my empirical study because it was the methodology that was most appropriate, given the focus and aims of the study. However, throughout the process of conducting the research, I have reflected on what it is about discourse analysis that I particularly value. When I started to reflect, it was easy to see that my identity in other areas overlapped with my decision making. Prior to training I had a long standing interest in the construction of mental health in society. I have often been left wondering about how different mental health difficulties are constructed in different cultures and how this impacts on what is done to support people with these difficulties. Of particular interest to me were those families, groups or cultures where a psychological language is not present and the impact that this can have on the construction of mental well-being. Given my interest in social constructionism, it now does not seem surprising to me that this is the area of research that I have chosen. The move away from cognitivism and towards discursive psychology and a critical stance (Hepburn, 2003), fits with my identity in other areas of my life. In my identity as a clinician I have often maintained a critical stance to more traditional cognitive based models and my areas of interest have been developed in more systemic, narrative and attachment based models. This seems to reflect the interaction between the different identities that I hold.

3.2.4. *Life outside of training*

I feel that the construction of my identity outside of the training experience is heavily intertwined with my identities within it. How I identify with others and the development of my personal interests before I entered training are what led me to, and continue to lead me to want to pursue a career in clinical psychology. Without them I am likely to not have been motivated to continue when I have faced rejection. This led me to consider the '*moral disposition*' (Weicht, 2009) of informal carers that can be constructed through discourse and whether I have experienced something similar personally that has attracted me to a career of this type. However, I feel that my identity outside training has also changed with my development on the course as I have developed a better understanding of myself.

3.3. Divergent identities

Not all of my identities have converged during the research process and I have been left feeling conflict at times. One area in which this was particularly noticeable was during the data recordings. During those group meetings that I sat in on I often felt that my identity as a researcher and my identity as a clinician did not marry up. I felt conflict between my need to remain neutral and not to involve myself in the discourse of the group and wanting to offer therapeutic support to people in discomfort. Prior to training I worked for a dementia charity and my role included facilitating a support group for carers, which further impacted on my desire to offer support and information during the group recordings. Of course it was necessary for my researcher identity to remain dominant in this situation, but I was aware of the internal conflict that I experienced.

I found further conflict of identities during the research process when exploring both online and face-to-face support groups. Part of my personal identity was to be quite sceptical about what online support groups could offer in comparison to face-to-face support groups. Although my thesis was not making a comparison of the two types of group, I am aware that I favoured face-to-face groups and I was therefore mindful to not allow this personal preference to influence my approach to the research. I felt the societal influence of the current economic climate, when I noticed what felt to be a sparse number of face-to-face groups during the recruitment for my study and did not want face-to-face groups to be abandoned because support could be offered at a cheaper price over the internet. At an unconscious level, I think I felt that an online support group could not offer the same level of support as a face-to-face group and that carers would prefer the latter. However, I noticed that my preconceptions might have been clouding my judgement and my feelings seemed to shift when conducting my literature review. Through careful reading of a substantial body of research literature, I was able to see that, in fact, online support groups could offer meaningful interventions in unique ways when compared with face-to-face groups. This reduced my sense of conflict regarding the two types of groups and I was able to recognise through considering the empirical evidence that both can be beneficial for carers of PwD.

Conflict has not only been present during the research process. As a trainee there are a number of pressures felt from different places. For me one particular area was the conflict between my clinician identity and my personal and research identities. There have been times when I have wanted to immerse myself in all aspects of my clinical role and my other demands have slipped to the back of my mind. I think that the conflict has come when I have not been able to fully immerse myself and either

demands from my personal or research identity have needed to compete with my clinician identity. This has sometimes left me feeling that I am not able to complete all of my roles to the best of my abilities. I have felt disheartened at not being able to do this and have experienced wanting to give up because of the dissatisfaction with my achievements. This has been especially prominent when feeling as though I have not been able to give as much time to the important people in my personal life as I have wanted to, which in turn has left me feeling resentful of my training related identities. I wonder if the conflict I felt between my different identities is also something that is experienced by carers. Carers are likely to have numerous identities, all with their own demands and I wonder whether the conflict between carer and partner/daughter/family member/friend is experienced with the most difficulty. Reflecting on my own experience has worked to increase my empathy for the difficult role that informal carers hold.

3.4. Constructing a Group Identity

The prominent group identity that emerged through the analysis of my empirical paper led me to consider the groups that I belong to and the group identities that emerge from these and the actions that are created from these group identities. Social identity theory (Tajfel, 1978) considers that self-concept is influenced by the groups with which we perceive we are aligned and so it felt natural to consider the influence of these groups in my own life. My reflections took me straight to consider the group identity of my training cohort and my individual identities that work as part of the group identity. I have wondered about the similarities and difference in aligning with my group compared with the carers aligning with their groups in the discourse from my empirical paper.

In a similar way to carer support groups, my peers in my training group have come to support one another through what seems to be the shared narrative of our training journey. Our individual experiences often converge and filter into a cohesive story of the journey from the start of training to nearing qualification. As our group identity has developed, when considering our discourse, a clear theme that has emerged is that those who are not training do not quite understand our experiences and what we have been through. In a sense this would even include other training cohorts because this has been our own particular collective training experience. When reflecting on this, it is already possible to see the development of the '*in-group*' and '*out-group*' identities referred to in Social Identity Theory or the '*us*' and '*them*' distinction made by the carers in my empirical study (McLeod, 2008).

The positive interactions that emerged from the discourse in my empirical paper led me to consider what the discourse of my group would look like. As a group we have often reflected that we have tended to be placatory when interacting with each other and this was especially true at the beginning of our journey. It has felt that often this was needed as a survival mechanism to overcome any struggles associated with the course and we have utilised different methods of support to do so. At this point in my reflective journey I made a direct comparison with the findings from my literature review. As a cohort it has not always been possible to support each other in person, for different reasons, such as a vast variety of placement locations and living in different places. Very early on in our training experience we developed ways of communicating using the internet, for example via a group on social media and an internet based group thread accessed on our smartphones. In a similar way to the meaningful interventions that were achieved for carers of PwD using online forums, our cohort online forums have been very important to me. This struck a chord with

my initial scepticism over online support groups and the initial clouding of my judgement as I have been able to experience first-hand the support that groups like this can offer. Without the reflection that has been involved in the research process, the importance of these groups may not have become so apparent.

Within my training cohort, the positive interactions have far outweighed any negative interactions but considering what the group discourse was used for by the carers of PwD in my empirical study led me to think about how this differs in my cohort group. There was a sense that the members of the face-to-face dementia support groups had a similar goal to understand and cope with caring for someone with dementia. However, for me, the construction of the training cohort identity has felt different. It is true we are all working towards the same goal as qualifying as a Clinical Psychologist and to develop an understanding of mental well-being as part of this goal, but it would be incorrect of me to assume that we are working towards a collective knowledge and understanding. The very nature of clinical psychology training allows the development of a variety of interests and will result in different practitioners. For this reason, there have been times when disagreement has played a role in our group discourse. *'Meaningful disagreement'* (Dalley-Hewer et al., 2012) has been found to be present in discourse as a way of drawing on life experiences which then leads to creating an understanding within the social context that it is applied (Wenger, McDermott & Snyder, 2002). This has led me to consider whether as a group, this is how we utilise disagreement in our discourse and to a certain extent I think this is how we have used disagreement. However, I have also reflected on the role that the group discourse takes in developing us as individual practitioners and that at times we have unconsciously sought divergent identities that fit with our particular areas of interest. It left me wondering whether, although the construction of a group identity was prominent in the discourse of the carer groups in my empirical study, there may

be times when individual carers are resistant or move away from this identity as it is not consistent with other identities that they hold. Now that I am entering the final part of my training journey, I can already feel that leaving the group identity will be hard and I understand that this might be something that carers also experience upon leaving a support group.

3.5. Conclusion

Reflecting on my research journey has provided me with the opportunity for personal learning. The fluidity of my own identities have been reflected in my learning and I have noticed the convergence and divergence between my identities. I have also been able to see first-hand the importance of social interaction and aligning with a group identity to support my own individual identities. Through this process it has allowed me to connect further to the carers in my research and helped me understand the difficult negotiation that can occur when constructing a new identity.

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Appendix A. Instructions for authors ‘Internet Research’



Internet Research

Author Guidelines

Manuscript requirements

Please prepare your manuscript before submission, using the following guidelines:

Format	Article files should be provided in Microsoft Word format. LaTeX files can be used if an accompanying PDF document is provided. PDF as a sole file type is not accepted, a PDF must be accompanied by the source file. Acceptable figure file types are listed further below.
Article Length	Articles should be between 2000 and 9500 words in length. This includes all text including references and appendices. Please allow 280 words for each figure or table.
Article Title	A title of not more than 16 words should be provided.
Author details	<p>All contributing authors’ names should be added to the ScholarOne submission, and their names arranged in the correct order for publication.</p> <ul style="list-style-type: none">• Correct email addresses should be supplied for each author in their separate author accounts• The full name of each author must be present in their author account in the exact format they should appear for publication, including or

excluding any middle names or initials as required

- The affiliation of each contributing author should be correct in their individual author account. The affiliation listed should be where they were based at the time that the research for the paper was conducted

Biographies and acknowledgements	Authors who wish to include these items should save them together in an MS Word file to be uploaded with the submission. If they are to be included, a brief professional biography of not more than 100 words should be supplied for each named author.
Research funding	Authors must declare all sources of external research funding in their article and a statement to this effect should appear in the Acknowledgements section. Authors should describe the role of the funder or financial sponsor in the entire research process, from study design to submission.
Structured Abstract	<p>Authors must supply a structured abstract in their submission, set out under 4-7 sub-headings (see our "How to... write an abstract" guide for practical help and guidance):</p> <ul style="list-style-type: none"> • Purpose (mandatory) • Design/methodology/approach (mandatory) • Findings (mandatory) • Research limitations/implications (if applicable) • Practical implications (if applicable) • Social implications (if applicable) • Originality/value (mandatory) <p>Maximum is 250 words in total (including keywords and article classification, see below).</p> <p>Authors should avoid the use of personal pronouns within the structured abstract and body of the paper (e.g. "this paper investigates..." is correct, "I investigate..." is incorrect).</p>
Keywords	Authors should provide appropriate and short keywords in the ScholarOne submission that encapsulate the principal topics of the paper (see the How to... ensure your article is highly

[downloaded](#) guide for practical help and guidance on choosing search-engine friendly keywords). The maximum number of keywords is 12.

Whilst Emerald will endeavour to use submitted keywords in the published version, all keywords are subject to approval by Emerald's in house editorial team and may be replaced by a matching term to ensure consistency.

Article Classification	<p>Authors must categorize their paper as part of the ScholarOne submission process. The category which most closely describes their paper should be selected from the list below.</p> <p>Research paper. This category covers papers which report on any type of research undertaken by the author(s). The research may involve the construction or testing of a model or framework, action research, testing of data, market research or surveys, empirical, scientific or clinical research.</p> <p>Viewpoint. Any paper, where content is dependent on the author's opinion and interpretation, should be included in this category; this also includes journalistic pieces.</p> <p>Technical paper. Describes and evaluates technical products, processes or services.</p> <p>Conceptual paper. These papers will not be based on research but will develop hypotheses. The papers are likely to be discursive and will cover philosophical discussions and comparative studies of others' work and thinking.</p> <p>Case study. Case studies describe actual interventions or experiences within organizations. They may well be subjective and will not generally report on research. A description of a legal case or a hypothetical case study used as a teaching exercise would also fit into this category.</p> <p>Literature review. It is expected that all types of paper cite any relevant literature so this category should only be used if the main purpose of the paper is to annotate and/or critique the literature in a particular subject area. It may be a selective bibliography providing advice on information</p>
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	<p>sources or it may be comprehensive in that the paper's aim is to cover the main contributors to the development of a topic and explore their different views.</p> <p>General review. This category covers those papers which provide an overview or historical examination of some concept, technique or phenomenon. The papers are likely to be more descriptive or instructional ("how to" papers) than discursive.</p>
Headings	<p>Headings must be concise, with a clear indication of the distinction between the hierarchy of headings.</p> <p>The preferred format is for first level headings to be presented in bold format and subsequent sub-headings to be presented in medium italics.</p>
Notes/Endnotes	<p>Notes or Endnotes should be used only if absolutely necessary and must be identified in the text by consecutive numbers, enclosed in square brackets and listed at the end of the article.</p>
Figures	<p>All Figures (charts, diagrams, line drawings, web pages/screenshots, and photographic images) should be submitted in electronic form.</p> <p>All Figures should be of high quality, legible and numbered consecutively with arabic numerals. Graphics may be supplied in colour to facilitate their appearance on the online database.</p> <ul style="list-style-type: none"> Figures created in MS Word, MS PowerPoint, MS Excel, Illustrator should be supplied in their native formats. Electronic figures created in other applications should be copied from the origination software and pasted into a blank MS Word document or saved and imported into an MS Word document or alternatively create a .pdf file from the origination software. Figures which cannot be supplied as above are acceptable in the standard image formats which are: .pdf, .ai, and .eps. If you are unable to supply graphics in these formats then please ensure they are .tif, .jpeg, or .bmp at a resolution of at least 300dpi and at least 10cm wide.

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<i>For books</i>	<p>Surname, Initials (year), <i>Title of Book</i>, Publisher, Place of publication.</p> <p>e.g. Harrow, R. (2005), <i>No Place to Hide</i>, Simon & Schuster, New York, NY.</p>

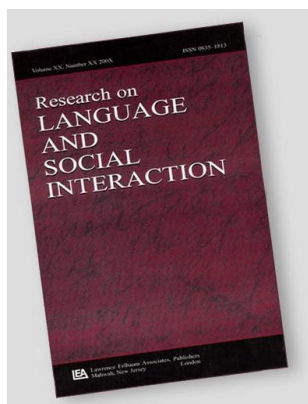
<i>For book chapters</i>	<p>Surname, Initials (year), "Chapter title", Editor's Surname, Initials, <i>Title of Book</i>, Publisher, Place of publication, pages.</p> <p>e.g. Calabrese, F.A. (2005), "The early pathways: theory to practice – a continuum", in Stankosky, M. (Ed.), <i>Creating the Discipline of Knowledge Management</i>, Elsevier, New York, NY, pp. 15-20.</p>
<i>For journals</i>	<p>Surname, Initials (year), "Title of article", <i>Journal Name</i>, volume, number, pages.</p> <p>e.g. Capizzi, M.T. and Ferguson, R. (2005), "Loyalty trends for the twenty-first century", <i>Journal of Consumer Marketing</i>, Vol. 22 No. 2, pp. 72-80.</p>
<i>For published conference proceedings</i>	<p>Surname, Initials (year of publication), "Title of paper", in Surname, Initials (Ed.), <i>Title of published proceeding which may include place and date(s) held</i>, Publisher, Place of publication, Page numbers.</p> <p>e.g. Jakkilinki, R., Georgievski, M. and Sharda, N. (2007), "Connecting destinations with an ontology-based e-tourism planner", in <i>Information and communication technologies in tourism 2007 proceedings of the international conference in Ljubljana, Slovenia, 2007</i>, Springer-Verlag, Vienna, pp. 12-32.</p>
<i>For unpublished conference proceedings</i>	<p>Surname, Initials (year), "Title of paper", paper presented at Name of Conference, date of conference, place of conference, available at: URL if freely available on the internet (accessed date).</p> <p>e.g. Aumueller, D. (2005), "Semantic authoring and retrieval within a wiki", paper presented at the European Semantic Web Conference (ESWC), 29 May-1 June, Heraklion, Crete, available at: http://dbs.uni-leipzig.de/file/aumueller05wiksar.pdf (accessed 20 February 2007).</p>
<i>For working papers</i>	<p>Surname, Initials (year), "Title of article", working paper [number if available], Institution or organization, Place of organization, date.</p>

e.g. Moizer, P. (2003), "How published academic research can inform policy decisions: the case of mandatory rotation of audit appointments", working paper, Leeds University Business School, University of Leeds, Leeds, 28 March.

<p><i>For encyclopedia entries (with no author or editor)</i></p>	<p><i>Title of Encyclopedia</i> (year) "Title of entry", volume, edition, Title of Encyclopedia, Publisher, Place of publication, pages.</p> <p>e.g. <i>Encyclopaedia Britannica</i> (1926) "Psychology of culture contact", Vol. 1, 13th ed., Encyclopaedia Britannica, London and New York, NY, pp. 765-71.</p> <p>(For authored entries please refer to book chapter guidelines above)</p>
<p><i>For newspaper articles (authored)</i></p>	<p>Surname, Initials (year), "Article title", <i>Newspaper</i>, date, pages.</p> <p>e.g. Smith, A. (2008), "Money for old rope", <i>Daily News</i>, 21 January, pp. 1, 3-4.</p>
<p><i>For newspaper articles (non-authored)</i></p>	<p><i>Newspaper</i> (year), "Article title", date, pages.</p> <p>e.g. <i>Daily News</i> (2008), "Small change", 2 February, p. 7.</p>
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<p><i>For electronic sources</i></p>	<p>If available online, the full URL should be supplied at the end of the reference, as well as a date that the resource was accessed.</p> <p>e.g. Castle, B. (2005), "Introduction to web services for remote portlets", available at: http://www-128.ibm.com/developerworks/library/ws-wsrp/ (accessed 12 November 2007).</p>

Standalone URLs, i.e. without an author or date, should be included either within parentheses within the main text, or preferably set as a note (roman numeral within square brackets within text followed by the full URL address at the end of the paper).

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- **Manuscript length** Submissions with English data ought be no longer than **8,000 words**; those with data in other languages with translation, no longer than **9,000 words**. If your ms. includes images, note that each will be counted as occupying the space of about 200 words.
- **Format** Prepare manuscripts according to the Publication Manual of the American Psychological Association (5th Edition).
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- **Languages: Specification** Submissions must specify, in the Abstract and at appropriate points in the text, the language variety or varieties reported (for example, Korean, American English, Brazilian Portuguese).
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Please allow twelve weeks for completion of the review process.

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Reflective Practice

International and Multidisciplinary Perspectives

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Appendix D. Original Quality Framework

Developing a framework for critiquing health research

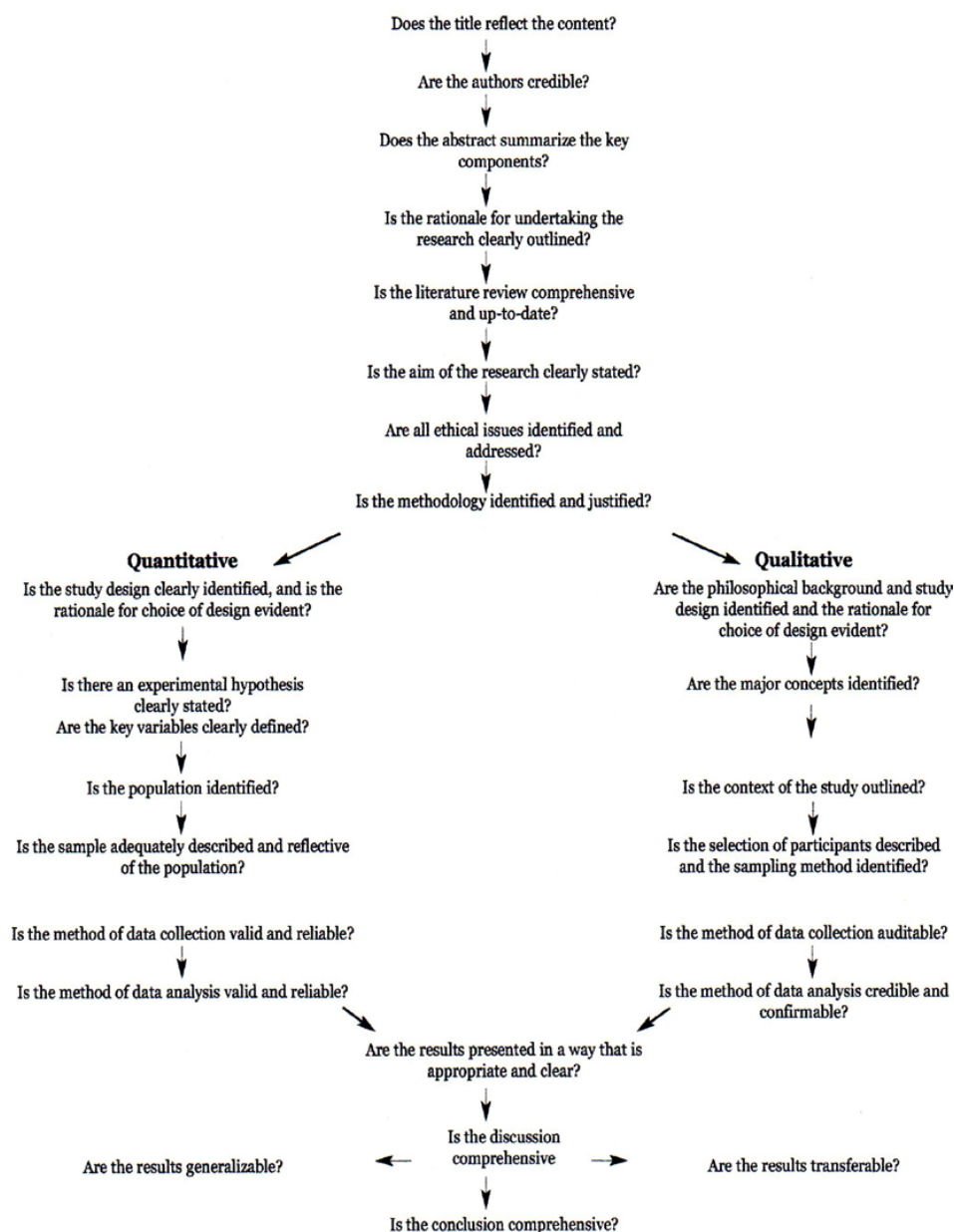


Figure 1: - Research critique framework

Appendix E. Quality assessment scores for reviewed papers

	Torp 2008	Pagan-Ortiz et al 2014	McKenchie et al 2014	O'Connor et al 2014	Christancho-Lacroix et al 2015	Marziali et al 2005	Torp et al 2012	Brennan et al 1992	White & Dorman, 2000	Brennan et al 1991	Brennan et al 1995	Marziali et al 2006b	Marziali et al 2006a	Gallienne, et al. 1993
Does the title reflect the content?	2	2	2	2	1	2	1	1	2	1	1	2	1	1
Are the authors credible?	2	2	2	2	2	2	2	2	2	2	2	2	2	2
Does the abstract summarize the key components?	2	1	2	2	2	2	2	0	2	1	1	2	2	2
Is the rationale for undertaking the research clearly outlined?	1	2	2	1	2	2	2	1	2	2	2	2	2	1
Is the literature review comprehensive and up-to-date?	2	1	2	1	1	2	1	2	1	2	2	2	2	1
Is the aim of the research clearly stated?	2	2	2	2	2	2	2	2	2	2	2	2	2	1
Are all ethical issues identified and addressed?	2	1	1	1	1	2	2	1	1	1	1	0	2	1
Is the methodology identified and justified?	1	1	2	2	1	2	2	1	2	1	1	1	1	0
Are the philosophical background and study design	1	1	1	0	0	0	1	0	1	0	0	0	0	0

identified and the rationale for choice of design evident?														
Are the major concepts identified?	2	2	2	2	2	2	2	2	2	1	1	1	1	1
Is the context of the study outlined?	2	2	2	2	2	2	2	2	2	2	2	2	2	2
Is the selection of participants described and the sampling method identified?	2	2	2	1	1	2	1	2	2	2	1	1	0	0
Is the method of data collection auditable?	1	1	2	1	1	1	1	1	1	1	1	1	1	1
Is the method of data analysis credible and confirmable?	1	0	2	0	1	1	1	1	1	1	1	1	1	0
Are the results presented in a way that is appropriate and clear?	1	2	2	1	2	2	2	0	2	1	0	2	0	1
Is the discussion comprehensive?	2	1	2	1	2	2	2	1	2	2	2	2	2	2
Are the results transferable?	2	1	2	1	1	2	2	1	2	1	1	2	2	1
Is the conclusion comprehensive?	2	2	2	2	1	2	2	1	2	2	2	2	2	2
Total	30	26	34	24	25	32	30	21	33	25	23	27	25	19

**Appendix F. Certificate of ethical approval and email confirmation from
Coventry University**



Certificate of Ethical Approval

Student:

Jenna-Lorin Spink

Project Title:

Social Construction of Identity in Dementia Caregivers and its achievements.
A Discourse Analysis of caregivers who contribute to face-to-face support
groups.

This is to certify that the above named student has completed the Coventry
University Ethical Approval process and their project has been confirmed
and approved as Medium Risk

Date of approval:

27 January 2015

Project Reference Number:

P29814

Ethics Request Updated
CU Ethics <omis@coventry.ac.uk>
22/12/2014 Jenna-Lorin Spink <spinkj@coventry.ac.uk>
Inbox



The following ethics request has been approved by Tom Patterson. The request has now been passed to the Module Leader, Departmental Ethics Leader or Faculty Leader for approval.

Ref:	P29814
Project Title:	Social Construction of Identity in Dementia Caregivers and its achievements. A Discourse Analysis of caregivers who contribute to face-to-face support groups.
Applicant:	Jenna-Lorin Spink
Supervisor:	Tom Patterson
Module Code:	D43PY
Module Leader:	Ian Hume

Appendix G. Research application sent to Alzheimer's Society



Research with service users: Application form

All applicants please note:

- The principal investigator must be sponsored by a recognised higher education learning institute (e.g. a University)
- The principal investigator must be studying at PhD level OR has already achieved a PhD Or higher Clinical qualification
- The project must have received ethics consent
- The project must be of local interest and show benefit or value to the Society
- The applicant must prove sufficient experience of working with vulnerable adults, knowledge of the intricacies of working with people with dementia and/or their carers and empathy towards the challenges associated with living with dementia
- Please submit the form to research@alzheimers.org.uk

Please attach with your application form:

- Proof of DBS clearance for working with vulnerable adults
- Any additional information which will enhance your application.
- ALL attachments and supporting documentation and the final letter of consent.

Date submitted:

Principal Applicant		
Title and full	Ms Jenna Spink	
Institution	Coventry and Warwick University	
Post held	Trainee Clinical Psychologist	
Department and address	Psychology and Behavioural Sciences, Faculty of Health and Life Sciences, Coventry University, Priory Street, Coventry, CV1 5FB	
Contact details	Telephone: 07793205523	Email:

If you are a student please state the degree you will attain on	Doctorate in Clinical Psychology DClinPsy	
Please list other applicants and institutes involved in the application	Applicant	Institute

Research title	Caregiver Identity: the impact of caring for someone with dementia					
Does this research have ethics approval from NRES?	No If yes, please include a full scanned copy of the IRAS application including all attachments and supporting documentation and the					
Research dates	Start date: December 2014			Finish date: May 2016		
Participants (please circle all that apply)		Vol unt eer	Pers ons with	C a r	Fa mily me	
Please detail the areas where you are aiming to recruit	I am aiming to recruit participants from the Warwickshire area.					
Is funding allocated to supporting any costs incurred by	Research costs are funded by the University, however I don't expect the Society to incur any costs for this study.					
Have you contacted anyone within Alzheimer's	No If yes, please provide contact details and dates But I hope to contact this group:					
Are there any conflicts of interest? (e.g. do you work or	No, I do not work or volunteer for the Society at the moment. I did however used to work as a dementia advisor and dementia support worker for the Islington Branch.					

How specifically do you hope that Alzheimer's Society will be involved?	The data collection will only involve the researcher attending the carer support element of the resource café and with consent from all members, recording naturally occurring discussions had by carers.
When do you expect Alzheimer's Society	Start date: May 2015

involvement to start and finish?	Finish date: October 2015
How do you intend to feed back the results to participants?	I will provide the participants with a summary report of the findings.
Why do you consider Alzheimer's Society to be an appropriate partner for your research proposal?	I would like to recruit participants from the Alzheimer's Society as they are one of the main resources for carers to attend support groups. I feel that it would be useful for the Alzheimer's Society to be involved for that reason and to feedback the results of the study to you.
Please detail your experience of working with people with dementia or other vulnerable groups	<p>I have worked as a health care assistant with people with dementia. I also worked as an Assistant Psychologist as part of a Memory Clinic and Older Adult Community Mental Health Team, where my role was to complete the psychological assessments to accompany the other assessment process to try to ascertain whether someone should receive a diagnosis of dementia.</p> <p>When completing my MSc I worked for the Alzheimer's Society as a Dementia Support Worker and Dementia Advisor offering support to both people with dementia and carers. I also co-facilitated a carer support group, which is where my interest in this area started.</p>

<p>Summary of project</p> <p>Please include project aim and objectives, a detailed methodology (including recruitment, anticipated number and location of participants) and details of dissemination plans to a maximum of 1000 words</p> <p>Please attach all appropriate documents with your submission</p> <p>Including;</p> <ul style="list-style-type: none"> - consent forms - information forms - questionnaires - interview templates 	<p><i>Summary</i></p> <p><i>The proposed study aims to qualitatively explore how carers of people with dementia construct their identity within face-to-face support groups and what this identity, including its action and achievement. The study also aims to investigate how rewards and challenges of caring are presented in the context of dementia. Previous research has looked at language in online support groups, however carers that access face-to-face groups can be qualitatively different compared to those using online support and therefore it is important to investigate this group as well. Approximately 4-5 hours of natural data will be recorded from discussions at support group meetings specifically for carers of people with dementia. To investigate the use of language in this social context discourse analysis will be used to analyse the data. By completing research in this way it is hoped that a better understanding of how carers identify with themselves and others can be gained. In turn a better understanding of the social context of caring for a person with dementia should help to support carers in their role and inform person-centred care. The study will take approximately 18 months.</i></p> <p><i>Aim</i></p> <p><i>The aim of the proposed study is to qualitatively explore how carer's of people with dementia who contribute to open face-to-face support groups discuss their caring relationship and express their identities within the context of dementia. Discourse analysis will be used to analyse how each of the carers present their identity in the language that they use, what the purpose of that language action is and what it achieves.</i></p> <p><i>It will be an explorative method to answer the following research questions:</i></p> <p><i>i) How is language used to construct the caring relationship of a person with dementia?</i></p> <p><i>ii) How do carer's present identity within their caring relationship and the context of dementia?</i></p> <p><i>iii) What is identity used to achieve within the social interaction of carers of people with dementia?</i></p> <p><i>iv) How are challenges and rewards of caring for a person with dementia presented in language?</i></p> <p><i>v) Can comparisons be made with previous research that has explored identity within online support groups?</i></p> <p><i>Desired outcomes</i></p> <p><i>This study aims to explore how the roles of care-giving within dementia is constructed. It gives an opportunity to explore social action in language of dementia caregivers that is socially meaningful.</i></p>
---	---

	<p><i>The desired outcome of the study is to explore how carers present different identities within their discussions and what these identities are used to achieve. A second outcome is to explore whether there are similarities and differences compared with previous research that has looked at how carers present their identities in online support groups.</i></p> <p><i>By completing research in this way it is hoped that a better understanding of how carers identify with themselves and others can be gained. In turn a better understanding of the social context of caring for a person with dementia should help to support carers in their role and inform person-centred care.</i></p> <p><i>Design and Method</i></p> <p><i>The approach that I will be taking is qualitative. I will be using Discursive Psychology and a Discourse analysis to answer the research questions.</i></p>
--	---

Continued

The data for this study will be gained from recordings of face-to-face support groups for caregivers of people with dementia. The data will be naturally occurring extracts from the support group discussions that focus around care-giving in the context of dementia.

Carers of people with dementia who are already attending existing carer support groups will be asked to take part in the study. The research department within the Alzheimer's Society will be contacted to gain permission to contact local support groups provided by the society. Once permission has been granted facilitators of groups will be contacted by letter to ask for permission to contact carers who attend their meetings.

Each carer will be given an information sheet and time to discuss the study with the principle researcher. As the researcher hopes to record the group discussion all carers must give consent before recordings can take place. All carers will then be given two weeks to withdraw their participation. If one carer withdraws no data from that meeting will be included in the analysis and findings of this study.

Attachments

I have attached my information sheet, consent form and debriefing sheet for you to look at. As I will only be recording natural conversations that occur at carer support meetings there is no questionnaires or interview templates. I have also attached my ethics approval from Coventry University.

Appendix H. Email confirmation of ethical approval from Alzheimer's Society

Tooke, Jane <Jane.Tooke@alzheimers.org.uk>

20/03/2015 Jenna-Lorin Spink

You replied on 23/10/2015 10:06.

Hi Jenna

We have had a very swift and specific response from our services. See below:

Sara Lawley, who is the DSM in Coventry is happy for this to take place but has specified a date of 28th April.

Can I ask you to contact Sara Lawley direct. Her e-mail is sara.lawley@alzheimers.org.uk. Her phone number is 02476 652602.

If this does not fit with your research let me know and we can try elsewhere

Regards

Jane
Evaluation Project Manager

TJ

Tooke, Jane <Jane.Tooke@alzheimers.org.uk>

Appendix I. Copy of Information sheet given to contributors

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF
WARWICK



Information for Participants

You are being asked to take part in a research study. Before you make a decision about taking part it is important that you have information about why the research is being conducted and what will be involved if you participate. Please read the following information carefully. If you have any questions about the study then please contact me.

Title: Caregiver Identity: the impact of caring for someone with dementia

What is the purpose of the study?

This study is interested in what happens in the conversations that occur amongst carers of people with dementia at real life support groups. This will include exploring how carers talk about the demands and rewards of caring for a person with dementia. Person-centred care focuses on the social aspect of dementia and dementia care and that is why discussions had in social interactions with other carers are of particular interest.

Why have I been invited?

People who care for a relative or friend with dementia and attend open face-to-face support groups for carers of people with dementia are being invited to take part in this study.

What does contributing to this research involve?

If all members of your support group consent to taking part in the study involvement will mean having a regular support group meeting recorded using a Dictaphone by the researcher leading this project. The researcher will also sit in the group to become familiar with voices, but will not contribute to the group in anyway.

Dean of Faculty of Health and Life Sciences
Professor Guy Daly Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Head of Department of Psychology
Professor James Tresilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

www.coventry.ac.uk

Will my information be confidential?

After the recordings have been made the researcher will transcribe what is said onto a computer. The recordings and transcriptions will be anonymous and there will be no identifiable information. The recordings will be stored in a locked cabinet. These will not be accessible to anyone apart from the researcher. Consent forms will be kept in a separate locked cabinet. Written transcriptions will be stored on a password protected computer and will be kept for 5 years after completion of the study.

Do I have to take part?

Taking part in the study is completely voluntary. If you decide that you would like to contribute then you will be asked to sign a consent form. You are free to withdraw from the study before, during and up to two weeks after the recording. If you decide to withdraw, no data will be used from the group that you were involved in so that your data is not used in anyway. To withdraw from the study you can contact the researcher or supervisor by using the contact details below and requesting removal of your recording.

Are there benefits and risks to taking part?

We hope that the data from this study will help us to think about how carers use support groups. In turn it is hoped that this information will help people support carers.

The data collected will be recordings of discussions held at face-to-face support groups. As this data is generated naturally it is hoped that there would not be any adverse effects of taking part. However if you are worried about your contribution or the recording itself please discuss with the facilitators of the group or one of the research team (details below).

What happens to the data collected from this research?

The research will be written up as part of a clinical psychological doctorate with Coventry and Warwick Universities. A summary of the findings will be sent to support groups that took part. It is hoped that the findings of the research will be published in an appropriate journal. No identifiable information will be included in reports or publication.

Independent advice?

If you are unhappy about this study or wish to make a complaint then please contact the researcher supervisor (details below).

Contact details

Researcher: Jenna Spink, email: spinkj@uni.coventry.ac.uk

Supervisor: Dr. Tom Patterson, email: t.patterson@coventry.ac.uk

Address: Clinical Psychology Department, Coventry University, Room JSG24, Priory Street,
Coventry, CV1 5FB. Tel: 02476888328

Appendix J. Copy of consent form given to contributors

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF
WARWICK



CONSENT FORM

Title: Caregiver Identity: the impact of caring for someone with dementia

Please read the statements below and tick the boxes to indicate your agreement, then sign and date at the bottom of the sheet.

I have read and understood the Participant Information Sheet ☐

I have been given the opportunity to ask questions about the research and what my contribution will involve. Any questions I had have been answered satisfactorily. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time during the recording and for **two weeks** following this. I understand that should I decide to withdraw prior to the two week limit my data will be destroyed. ☐

I give permission for the carers support meeting that I take part in to be recorded and transcribed. ☐

I understand that all documents relating to the research, including audio recordings, will be kept anonymously and no identifying information will be used. ☐

I understand that the individuals supervising this research will look at the transcript of my interview but that I will not be identifiable to them. ☐

I agree to participate in the above study. ☐

Participant signature..... Date.....

Researcher signature..... Date.....

Dean of Faculty of Health and Life Sciences
Professor Guy Daly Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Head of Department of Psychology
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Appendix K. Extract from Transcript 4

- 172 Laughs
- 173 P6: You're an only child aren't you?
- 174 P5: No I have a brother.
- 175 P6: Ok, ok.
- 176 P5: But when my mother was first diagnosed, well she wasn't officially diagnosed, but the memory
 177 clinic did carry out a diagnosis she went from slight to memory loss to complete out and out in a year
 178 :so: um yeah they said there was no point putting her through it all uh but from interviewing and
 179 whatever tests they did (.) asking questions and showing her pictures and from they ascertained from
 180 me it looks like she has got vascular °dementia° yeah. And my brother wanted to put her into a home
 181 straight away and we sort of like >fell out<. And we haven't spoken since. Sighs (.) °that's me°. Please
 182 let somebody else speak. Because I need to drink this tea before it gets cold.
- 183 Group laughs
- 184 P2: No I haven't really got a lot to say sorry (laughs).
- 185 P1: Well tell us about, you are caring for your husband? Well tell us about him, when he was diagnosed
 186 and that sort of thing.
- 187 P2: Um he was diagnosed 6 years ago with um slow dementia, but over the years and with his other
 188 things that he has got wrong with him, nobody seems to want to listen (becomes teary) sorry.
- 189 P1: Yes, it is ok. We all understand. What do you mean when nobody wants to listen? You mean your
 190 GP or (.)
- 191 P2: No (continues to be teary)
- 192 P1: It's ok we all understand around this table. → empathy for group cohesion.
- 193 P5: What's your name?
- 194 P1: (says carers name)
- 195 P5: I've had a weepy every now and then when I first got here. I couldn't understand my Mum's
 196 condition. It took me, because I had nobody to give me any advice (.) prior to my coming to this group
 197 a lot of the time I thought, you are doing this on purpose Mum. I really had no idea, you know like, half
 198 the things we used to argue about, I'd think you are looking or a towel and you have got it in your hand.
 199 You know and then she would put it down and say "where?" And I would say WELL YOU'VE just put
 200 it down. "No I haven't!"
- 201 P1: But when you get the diagnosis I found, after we got the diagnosis, I don't know if you found this,
 202 that I was a lot calmer because um I could understand well that's not just (husband's name) being bloody
 203 minded, you know, that's there is a reason for it. Whereas it is a bit of a shock when you get the
 204 diagnosis, nevertheless I always encourage people if they are even just slightly worried to get the
 205 diagnosis as soon as possible.
- 206 P5: An official one from the hospital
- 207 P1: Yeah (.) do you want to fill us in a bit more?
- 208 P2: No, not at the moment sorry → Not cohesive with the group motivational?
- 209 P1: Ok, that's fine, that's fine. yet. Identity things can be ok after a diagnosis isn't shared yet.
- 210 P5: How is your GP? (directed at 2). Is he well is he or she good you know? yet.

211 P2: He is, he is very good.

212 P5: What practice?

213 P2: Names practice

214 P5: Oh, is that where (says another carer's name) (doctor's surgery name)

215 P1: Pass I don't know.

216 P5: That's another one of the carers who comes here

217 P1: You mean (name of carer)

218 P5: Yes, yes

219 P1: The one that normally sits here?

220 P5: That's right yes.

221 F: Do you want to just (facilitator to last carer)

222 P6: No let the others, go

223 P1: We're all done. Over to you

224 P6: Well my name is (says name). I can understand um what the lady is saying because when my first,
225 my husband first had this dementia alzheimer's I knew nothing about it (.) um well that's about 21
226 years now I have been dealing with that and he had a doctor that you couldn't even talk to. When you
227 talk to the doctor the doctor would say you are telling me how to do my job and that, so um I said I
228 had to get him on to my doctor because I have a very good doctor, but when, when I say to him look
229 I've been married to this man for so many years and we have been together you know when your
230 husband changes and I always said when you are retired, when you retire, you are looking to have a
231 good time with your husband, not your husband turn on you and as you said I also think wow this man
232 (about husband) must be doing this on purpose why has he waiting until we retired to behave like that
233 and those days you never knew much about it even the doctors because it was just coming into focus
234 anyway um I had to get the hospital and all and so I had a mental health that used to come to my home
235 and she realised what was going on so I said to her look I am going to call a meeting because I am the
236 type of person I don't just let something rest if I know that I am right I have to fight you know. I had
237 to get the hospital staff and the same doctor and the mental health and she say she would come to the
238 meeting and she would speak up for me because she herself she tried and he just. She wrote letters she
239 do everything and he just said you are just trying to tell me how to do my job, but then we had the
240 meeting with the hospital, the mental health, the doctor, my husband and doctor we all was there and
241 he stand in front of all of us and say he doesn't know what I am talking about and I never say to him
242 that my husband was doing these things. So the mental health lady she says "No, you are wrong." She
243 says "I have the copy of every letter I wrote to you and you never replied and when I phone you, you
244 say to me you trying to tell me how to do my job, so I am glad that (name of carer) called this
245 meeting." So then I agree with the hospital, with the mental health, if I could get him changed to my
246 doctor because he didn't want to let him go, you get what I mean, and they worked everything out that
247 he can go to my doctor and since he went to my doctor things has rolled on, because my doctor is very
248 good and he help in every way. He do all the research and if he sent him to (hospital name) and I'm
249 not happy and I ask him for a second opinion he will send him to another hospital and they find out all
250 that was going on.

251 P5: (Name of 6) when you were first talking about doctors, when I was first um asked for advice off
252 my GP for my Mum, the same doctor that we are currently seeing now, just pointed to the back of his

empathy

*supportive
carer?*

*moves onto
powerless.*

Things can change?

253 office and said there is some paper work there that you can take when I first said I think there is an
254 issue with my Mum's memory. That same doctor you know now um (.) He (.) he quite happily will
255 see me at a drop of a hat when I phone up the surgery and say it is for my mum and he will always ask
256 me what I would like to be done, which you know I think is really good and he is just there to sort of
257 maybe offer advice on medicines and so on.

258 P6: Well this doctor that my husband had he always says if your husband wanted you to know he
259 would tell you. I say, but with my husbands condition I think I should know right and that is why I
260 insist to change him, but with him whenever you go to the surgery the surgery would be full of people
261 and he would be outside drinking and smoking. He always drunk and I says well how can you tend to
262 patients if you always drunk and he to say anything to him he would just abuse them. I say I don't
263 know where you come from, but doctors don't behave like that, but in the end a lot of people died um
264 through him because when he drink he give them the wrong medication. He give my husband the
265 wrong medication and when he went to the day centre at um (name) he had a German doctor and the
266 doctor says. How is your doctor? And then I say you look on the record who he is and I have never
267 heard a doctor swear like that she says this man every patient that come here to me. He always giving
268 them overdose or the wrong medication. So

powerless

269 1: He must have been struck off by now. This is a long time ago wasn't?

270 6: He stuck off now

271 1: This is a long time ago though wasn't it

272 6: Yeah but when he first, so what happened she decide if the patient don't speak there is nothing she
273 can do so then the patients decided to speak up about what was going on because some of them had it
274 going, had too many people was dying and um they struck him off and he is not allowed to um work
275 again. But he was so clever that he had a lot of friends in top places and then he went and he was
276 working private.

Fighter

277 5: Oh well there is always going to be someone like that. Do you get support (B name) from um local
278 authorities or care.

279 2: No

280 5: Uh so no one comes into, I mean you're ok bathing. How far has it got?

281 2: No he is not um. He's not that far advanced. He can, he goes to a lunch club every day and he is on
282 his mobility scooter, but that is as far as he will go on his own.

283 5: Right

vulnerable

284 2: I do everything else

285 5: I mean do you notice him doing less because of

286 2: Oh definitely, yeah. And over the years. I mean even our children notice he's getting worse (teary)

287 5: So is the memory clinic aware of him?

288 2: Um no they discharged us.

vulnerable

289 1: Discharged you?

290 2: Yeah

291 5: Why?

292 1: Is he not on any medication?

293 2: He is on medication, but not for his memory.

294 1: Oh right, because we were discharged from the memory clinic because (husbands name) not on any
 295 medication. Which was fine. I have recently had a visit from the dementia navigator service and uh
 296 and when a chap came, it was just uh yesterday, uh Monday, and a young chap came round and um I
 297 said I don't really need you and he said well actually what we are doing now is checking up on the
 298 people who are not under the memory service because um, because, because they are not on any
 299 medication, so it maybe that you can benefit from a visit from the dementia navigators service. What
 300 that does

301 F: What they do is that they visit anybody, um who has these kinds of issues and for like guidance and
 302 support and they give you an overview about the services that are available in the area, so they can
 303 literally navigate you on to be able to for you to be able to access the best support so, so of course
 304 there is them and I can give you the details and I think they are from the NHS.

305 1: Yes NHS.

306 F: Mentions other services, but I think the navigators would be the best people to contact and to talk
 307 to.

308 1: Do you, does he get attendance allowance? Do you know about attendance allowance?

309 2: He gets an attendance allowance yes.

310 1: Oh right because that's not means tested so that is the first thing to do get.

311 2: But see he can get that and everybody in authority tells me I should get a carers allowance, but
 312 because I get a state pension, I can't get it.

313 3: I think you can get one or the other, you can't have both.

314 1: Both yeah

315 2: But then how comes people that are just becoming carers (.) they are getting everything?

316 5: Well

317 2: And I've been to two different people for counselling right and they asked me the same questions
 318 right and as soon as I say no (.) they won't let me see them again. And the answer no they ask me am
 319 I suicidal and I say no. Do I ever intend to do him in and I say no and that's it. I would sometimes I've
 320 got to be honest.

321 Group laughs

322 P1: we've all been there. *empathy / understanding we are all the same*

323 P6: But then as soon as you say no they don't want to see you again, but if I was to say yes I am
 324 suicidal what would they do follow me home? And then cart me off.

325 P5: Probably just a means to carry on seeing them.

326 P6: If you say that they will take your husband and cart him off.

327 P2: But why lie?

328 P6: No don't lie.

329 P2: No if I feel that he is getting on my nerves which he does and I probably does get on his I just go
 330 out for a walk.

Fighters?

info giver.

vulnerable

331 P5: Do they not redirect you maybe to groups like this where, because sometimes, I mean I have
 332 found this very therapeutic. There was all sorts of things, you know, that I couldn't understand and
 333 like washing my Mum. I couldn't understand why she didn't want water or like water and she would
 334 scream if I tried to wash her hair or anything like that and then one of the chaps that attended this
 335 group, he just said well why don't you just use a little face wipes, to do it. So I started with that and it
 336 just gradually progressed um until now she is quite happy that I can wash her top to toe or whatever
 337 the expression is, but she still won't get in a bath or anything. As I said would they not direct you to
 338 any other groups, like this?

339 P2: Um they have mentioned in the past, but it was the point of walking through the door.

340 P1: Yes well that's um. Well you've done well to come today then. So well done.

341 P2: Well I found more advice from family and friends than correct people.

342 P1: Well that's what we are. We [are yeah]! → group identity.

343 P2: [I've got] two children and they both say to me make sure he's got something to drink, he's got
 344 his medication, he's got something to eat, make it or if he wants to do it himself, which he sometimes
 345 does and then you do your own thing. Because if I was to stay with him, I most probably would do
 346 him in. → it's serious more truth.

347 P1: But that's good that you can get out and leave him like I can.

348 P2: I do worry

349 P1: Oh the guilt. Tell me about it

350 P5: where is he at the moment?

351 P2: He will be at home now

352 P5: Because you know I was doing, which is I'd get so wound up, so frustrated and so angry I'd leave
 353 the flat go and sit in my car, put the radio on, listen to music, watching the flat to make sure that she
 354 wasn't going to leave and go anywhere without me. You know it's not nice to talk about, but I
 355 suppose I have to watch her (.) like almost 24/7 so I am really glad that she goes to the day care centre
 356 because she has no idea what to do when she needs to go to the loo, she doesn't know what to do so
 357 she will go as far as taking everything off and sometimes she will be completely naked and she will
 358 just go wherever she is standing so the knock on effect of that is I sleep with my door open watching
 359 my door. So every hour or so I am awake. I find that the only time that I get a really good sleep is
 360 when I drop her off at the day care centre come home and then go straight to bed you know like so I
 361 will sleep whilst she is at the day care centre so if she is up and about a lot of the time I am just sitting
 362 there with my tablet late and night just watching her bedroom door you know like watching a film on
 363 my tablet or playing a game or something and I go through the whole night like that (.) because on
 364 occasions where I have dropped off (.) I've woken up to something that I need to clear up. You know
 365 it's

366 P1: Does he sleep at night? Do you get a decent night's sleep?

367 P2: He gets a good night's sleep. I don't. He is COPD that is to do with the lungs, his breathing and
 368 coughing and everything. No he is coughing all night and then he is on his puffer no.

369 P5: So you share a room?

370 P2: Yeah we have got a one bedroom flat.

empathy
an understanding
through group cohesion

supportive cover

I'm protecting him by doing what I am doing.

understanding

Through group cohesion.

I'm the one who is vulnerable.

371 P1: Oh gosh, cor I have to say I haven't slept with my husband for years (laughs) it was a great [relief
372 when we stopped.]

373 P2: Well a few years back about 8 years ago, I insisted on single beds.

374 P1: Oh that's good then.

375 P2: Because um

376 P1: That's a start

377 P2: He's, he's been through a lot, which a lot I understand. Now to test him for Huntington's Disease.

378 P5: What's that?

→ I'm an understanding carer.

379 P2: That's the shakes and everything. He is continuously shaking right.

380 P1: That's a genetic decision.

381 P2: But, yeah um.

382 P1: Did one of his parents have it?

383 P2: No he hasn't got it, but for his shakes they can give him some medication, but they have bad side
384 effects and so he has decided not to take them. And all day if I'm in we've both got reclining chairs,
385 right he sits that side of me and all the time his feet are on the move like this and while you are trying
386 to watch telly or do something you know. And the doctors will tell you, he can't help it, and I'll say
387 well when I say something when it really does get to me he can stop it and I if he don't know he's
388 doing it. This may sound silly, but why can his feet go in tune with the music you know.

389 Group laughs.

390 P1: Is it definitely Huntington's [not Parkinson's]

391 P2: [No it's not]

392 P1: Not Parkinson's?

393 P2: Not Huntington's, he's been tested for that and they say that he can have medication, but he
394 refuses to because they told him it has side effects. I said not everybody suffers from the same side
395 effects from the medication.

→ he won't even take the medication.

396 P5: (5) can I just, my Mum does the same, that and it is part of her condition with Alzheimer's. She
397 will sit there and she'll (rubs hands).

398 P2: Oh yeah (in agreement)

399 P5: and she will rub her hands or her arm incessantly. She won't stop and when you are trying, you
400 know like when sometimes you are just with individuals and you will sit back and their very quiet and
401 ones reading a paper and one is watching the TV, but when you have got somebody doing that it's
402 almost like you have got somebody pinching you and they won't stop.

403 P1: Drives you bonkers.

404 P5: Exactly, but she does not realise she is doing it. And if I say Mum and she will just stop, but if I
405 leave her to it. It's very much like she is lying in bed and she did this whilst she was at hospital she
406 was lying asleep or well I thought she was asleep and then her hand came up (.) and she was reaching
407 out to grab something then it came down and she found the sheet, that was covering her, so her other
408 hand came up and then she just ripped it in half.

evidence that she doesn't know what she is doing

"Supportive" carer => giving advice from own experience

409 Groups grasps and laughs.

410 P5: And then I thought to myself. I bet you pay attention to me now. Thinking you know like, you
 411 should have listened to me befo.... I don't mean my Mum, but you know like the nurses and I mean
 412 she has ripped shoes, she doesn't leave any buttons on cardigans. So I don't buy cardigans any more.
 413 She has ripped two coats, duvet.

414 P1: She really is strong.

415 P3: This is mega fiddle isn't it? Laughs

416 P5: That's right, one of the ladies that attends here, made these pillows for us, they were copies of
 417 what the Alzheimer's Society provide which was a pillow case with zips and buttons and all sort of
 418 fiddly things, but bless her they weren't that tough. It was with flimsy cotton and I gave it to my Mum
 419 and it lasted literally that evening. It was gone. Like half an hour and like every button and it was
 420 gone. And so his shaking may well be nothing do with huntington's, but more to do with his
 421 Alzheimer's.

422 P2: But you see when he has had his puffer as I call it, he will sit and play with it and fiddle and it
 423 makes a noise because it is bashing against his ring and when I say to him, why are you doing that
 424 while you are watching telly? "Because it's in my hand" *Action? For it to stop?*

425 P1: Yeah

426 P3: At the care home, one lady was, she just spent day in and day out (taps the desk), or thumping
 427 with her feet. Yes if there was music on she would be thumping and tapping to it, but you could even
 428 hear it if you were on the floor below. So the staff had to listen to that, that was her, you know, she
 429 needed to do it (laughs). It was kind of just part of her and when and well she died at some point
 430 during those last years, but um it didn't seem the same, because there wasn't that sound anymore.

431 P2: So in a place like that with mine, do you say something to them? Do you ignore it? Or what do
 432 you do? *Needs help.*

433 P5: I sometimes ignore it, but uh

434 P2: But when you ignore it, doesn't it, doesn't it grate on you?

435 P1: Well of course it does. If it bashes on your ring. I hate to say it, but could you take his wedding
 436 ring off so it wouldn't bash against it. If that's one of the things. I don't wear a wedding ring anymore,
 437 but that's for a different reason, oh I was a masseuse and it used to hurt and now I can't get it on, so
 438 you know, and I feel my marriage is stronger than my wedding ring, so would that be a temporary
 439 solution to that anyway? *Supportive.*

440 P2: Um

441 P1: Or maybe he wouldn't. You mightent get it off anyway.

442 P3: Put tape round.

443 P1: Or tape round it even better

444 P2: You ^{see} say he thinks I want him put in a home so somebody else can look after him and I can have
 445 my life, but that's not true and when I, I do say to everybody I just feel that he's got something against
 446 me. 49.34 *Vulnerable.*

447 P3: It [sounds like that]

448 P5: [Because it's not that advanced]

449 P1: But he's not, for want of a better word, he's not in his right mind. You know he's not as he was 20
450 years, is he? *disclaimer*

451 P2: I know, but I've got to have a life as well as him.

452 P1: Absolutely, you definitely need some help and, and you said there was a nurse that sent you here,
453 what (inaudible).

454 P2: She was the COPD nurse, she wasn't to do with the um dementia.

455 P1: Right, but um well thankfully she sent you here

456 F: gives contacts for the dementia navigators.

457 P1: We had the manager from, I can't remember her name now, I've got it somewhere, and she said
458 do please get in contact and they can help you with where to go. It's not that long ago that she came, 6
459 months or something. *supportive cover.*

460 P4: Is that the lady from down the road?

461 P1: No that's the woman from the carer's hub.

462 P1: But do pluck up courage and give them a ring and say that you have been here. I have, I mean the
463 person that I, but he wasn't the manager, I have actually got the name of the manager at home if you if
464 I gave you my phone number you could ring me. So you have got a name to ring up and say could I
465 please speak to.

466 P5: It sounds as if you are exactly where I was um when my Mum was far more, even though she
467 couldn't remember me she was far more aware of everything that she was doing her. Um and so to, so
468 to try and correct what he does, which is what I used to do with my mother would be, It just used to
469 make her really angry. I suppose what I learnt from that is that I wouldn't. I just take myself out of the
470 equation and move into another part of the room or I know you said he goes to a lunch club. If he
471 could, the day centre, they spend all day there between 8 and 6. *supportive*

472 P2: No he won't have anything like that. *using own experience to offer advice*

473 P5: Well luckily my mother wouldn't know anything different now. Yeah um I

474 P1: It sounds like you need something

475 P5: Yeah *↳ Motivation to change something?*

476 P1: And if you can leave him at home because you feel that he is alright. I know about the guilt and
477 the worry, but if you left him at home, whilst you went out for a couple of hours [to do something]

478 P2: [Oh I do] *↳ it doesn't mean you are a bad carer.*

479 P1: Oh you do anyway, but he doesn't. You see (5's) Mum is a wanderer, but with my husband, he is
480 locked in and he doesn't know where the keys are anymore, so the worst thing that could happen now
481 is if the house catches fire and I do think about that all the time, but um he you know he wouldn't
482 leave the house, which means I can get out and that keeps me sane.

483 P2: Me going out it does help. *↳ I am a good carer. I worry about these things.*

484 P5: I mean when he's like that and you can't relax in the front room. What would he do if you went
485 into the bedroom and watched TV in there? Or read a book or magazine there? And left him in the
486 living room. What would he do then? Would he follow you?

487 P2: yeah

488 P5: Oh right so you, yeah that's not easy. That's not easy.

489 P6: My husband used to so the same. Follow me everywhere, shouting for me and say like if I came
 490 here today and if he was at home by the time I got home, his trousers he would cut them and pull his
 491 string out and cut off all the buttons, cut off the belt and I used to say, just how you feel. Why are you
 492 taking this out on me? What have I done? Why do you hurt me like that? He would just laugh.
 493 Everything I say he would just laugh, but I come to the conclusion that um (name) says to me you
 494 realise what he is doing with the trousers so buy the one with the string and when he find out that he
 495 had trousers with a string. And he would cut the trousers in the back. So when I wash it clothes I lock
 496 them away. Every day when I bathe him because I don't, like (1), I don't wear my wedding ring
 497 anymore neither, because now I have to wash him and I find when I was him it, my hand swell or
 498 something and it is difficult with a ring, but anyway forget about that. If he is on his own watching
 499 television by the time I go home the television would be broken. He would interfere with every button
 500 and make sure the television don't work. Things like that.

501 P5: That's a cry for attention though. I have found that with my Mum as well. I don't give her any
 502 down time. When I am with her. I am constantly talking to her, touching her, asking her to follow me,
 503 even when she is sat down and she is dozing off and you think five minutes peace and quiet or I can
 504 do what I want. I shake her and say come with me and the more attention I lavish on her now uh the
 505 calmer she is. She is really, really calm.

506 P1: Do you get some help from your children? Sorry to interrupt, but you said your children are they
 507 adult? Are they local?

508 P2: Well they are adults, no they don't live at home

509 P1: Are they near by?

510 P2: No one is (location) and one is (location).

511 P1: Oh °so not that far°.

512 P2: It's like people, when they come, they turn round and say, Mum why are you saying all these
 513 things.
→ I'm vulnerable because people don't understand.

514 Group agrees

515 P2: But we spent Christmas Day and Boxing Day with my daughter and she said to me. I don't know
 516 how you do it and now she realises that when I tell her things it's not just me.
→ serousness - others couldn't do the job.

517 P1: Well that's good.

518 P2: And that makes me feel better. You know as you say talking here. I feel a thousands times better.

519 P1: Well look we've all been there *→ gone from not feeling the same to feeling the same*
So much better.

520 P2: But you know when you think you are on your own all and we do argue a lot. You know and it, it
 521 could be *over the course of the group!*

522 P1: Well that's called marriage

523 Group laughs

524 P1: You know we have been married for 48 years and there have been, well actually we don't argue
 525 now because.

526 P2: Well we have been married longer than you, but um no it is hard. You know if I was to go home
 527 and if the front door was open and I said something. If I tell him no you have come in and left the

528 door open, no I haven't you are in a bad mood and you are having a go at me. And I can't prove it to
529 him and when I take him out now. If I take him out at weekends and we use his wheelchair because he
530 has got a bad hip. He will ask me for something and it might have been something that we had when
531 we first got married and it doesn't exist anymore and I go around the shops looking and when I take
532 him out right we will go in Marks where we used to get it and we look around and he'll say "Oh they
533 don't do it". Well I told you that so many times. Why can't you believe me?

534 P3: His mind might be back in that era. Because that's the thing, the mind transposes eras and it
535 maybe an earlier time in life and he expects to find things and he can't believe it when they don't
536 make them anymore you see, this is it, it's another guessing game as to where the person is at that
537 moment and it can change from moment to moment in whatever age they think they are or you are
538 and whatever time of life they are in right back to childhood. *supportive answer.*

539 P5: Do you mind mean asking (2) why the memory clinic discharged you if um (.) I mean do they not
540 perceive him as having a problem?

541 P2: Um I think it was mainly me, when I was asking them questions and they would not answer my
542 questions. *some of these things are my fault.*

543 P1: I think it may be as I have said if he is not on any medication, the thing about memory clinic is
544 that they are following up and monitoring people all the time and people go back every 6 months or
545 something and so they can assess how the medication you know, but when we stopped taking the
546 Aricept which was ages ago now, but after about six months the doctor there said well I am going to
547 discharge you because there is no point, there is nothing for us to follow-up with you. Just go back to
548 your GP if you need any help. *supportive*

549 P5: But did they give you medication? *changed subject. knowledgeable?*
550 P2: No he's not on any, but one of the questions I really would like answers to right. If I turn round
551 and tell him that is a pen and he says it's a cigarette (do I agree with him, do I argue with him, do you
552 have to always give in to him so he is always right or do you correct them?

553 P5: I think if you try and correct them all the time you become more frustrated because

554 P1: Absolutely

555 P5: Because they will continue this and as the memory becomes progressively worse, it's almost as
556 though they are a child in the back seat. "Are we there yet? Are we there yet?" and they will just keep
557 going on and on. They have an endless amount of patience because they are not realising that they are
558 doing it over and over again and so

559 P2: I think he does

560 P1: But has he actually had a diagnosis of Alzheimer's or dementia?

561 P2: Uh yes. I've got letters to prove that he has got dementia.

562 P1: Well then he doesn't know. He can't know. *repetition*

563 P2: Well then how comes if he like um yesterday, when the nurse came to us. He will turn round and
564 she will ask him a question and he will ask me and I will say yes I told you that yesterday and he says
565 oh yeah you did tell me. You know and it's not funny.

566 P1: But he is probably a bit frightened himself.

567 P5: And they do know what to say and do

568 P1: yes, they become devious